



Women Enabled International Submission to OHCHR: Birth Registration for Children with Disabilities

Women Enabled International (WEI) welcomes the opportunity to contribute to the forthcoming report by the Office of the High Commissioner for Human Rights (OHCHR) on best practices on birth registration and the right of everyone to recognition everywhere as a person before the law, as indicated in the Human Rights Council Resolution 34/15. WEI works at the intersection of women's rights and disability rights to advance the rights of women and girls with disabilities around the world. Through advocacy and education, WEI increases international attention to—and strengthens international human rights standards on—issues such as violence against women, sexual and reproductive health and rights, access to justice, education, legal capacity, and humanitarian emergencies. Working in collaboration with women with disabilities rights organizations and women's rights organizations worldwide, WEI fosters cooperation across movements to improve understanding and develop cross-cutting advocacy strategies to realize the rights of all women and girls.

Part I of this submission outlines why birth registration is essential to safeguarding the rights of children with disabilities, and then identifies barriers to birth registration for children with disabilities, gender dimensions of the issue, and special considerations for emergency situations. The submission then identifies in Part II the international human rights standards that underpin the right to birth registration for children. Finally, in Part III, the submission provides recommendations, including some examples of good practices to promote widespread registration of the births of all children, including children with disabilities.

I. Barriers to Birth Registration Expose Children, Particularly Children with Disabilities, to Human Rights Abuses

Although the Sustainable Development Goals call in Target 16.9 for birth registration for all children,¹ birth registration continues to be a universal problem that affects all children. According to The United Nations Children's Fund (UNICEF), the births of nearly 230 million children under the age of five have never been recorded.² One in three of these unregistered children lives in India, making India the country with the highest number of unregistered births by a wide margin.³ Further, the majority of countries with the lowest levels of birth registration are found in sub-Saharan Africa. In Somalia for example, only three percent of the births of children under the age of five are registered.⁴

The UN Convention on the Rights of Persons with Disabilities' (CRPD) Article 31 requires disaggregated data collection regarding persons with disabilities.⁵ However, there is still a lack of reliable statistics concerning children with disabilities. Most recent data reveal that approximately one billion persons worldwide or 15% of the world's population live with some sort of disability today.⁶ The World Health Organization (WHO) estimates that more women than men are disabled during their lives, with 19.2 percent of women compared to 12 percent of men.⁷ Although reliable data on children with disabilities is even more difficult to find, studies estimate that between 93 million and 150 million children live with disability globally.⁸

Why is birth registration important to children with disabilities?

Birth registration provides important protections to all children. Birth registration is closely linked with nationality, as birth registration serves as vital evidence of a child's place of birth and parentage to support a child's claim to citizenship on the basis of place of birth (*jus soli*) or descent (*jus sanguinis*).⁹

Children who are not registered may face statelessness and may be excluded from the benefits of citizenship.¹⁰

Failure to register the births of children with disabilities can carry severe consequences. Non-registration of children with disabilities, for instance, can put them at a high risk of abuse, institutionalization, or even death.¹¹ Birth registration of children with disabilities serves as an essential element to the protection of children with disabilities and ensure their “visibility.” Children with disabilities whose births go unregistered, in contrast, are at risk of institutionalization where they can be subject to abuse, torture, violence, and neglect.¹²

Moreover, birth registration can be an essential step to accessing necessary services, including education, health care, and other community services and supports. The Committee on the Rights of the Child (CRC Committee) has noted that children with disabilities may be denied access to education where their births have not been registered and they lack identity documents. For instance, in concluding observation to Albania, the CRC Committee expressed concern that children with disabilities who lack birth registration and other identity documentations are refused access to school and face barriers in accessing education.¹³

Birth registration provides a vital safeguard to promote the visibility of children with disabilities, ensure that they are represented and counted within government statistics, and offers legal protection for them to access their rights, including the right to health, education, and other essential support services.¹⁴

Barriers to birth Registration of children with disabilities

Despite the fact that birth registration is essential to safeguarding the rights of children with disabilities, children with disabilities disproportionately do not have their births registered due to a variety of factors,¹⁵ including discrimination in both law and practice, physical and geographic barriers, and financial considerations.

One considerable obstacle for the registration of children in general is accessibility of registration facilities to those who live in remote areas. The distance to the nearest registration center as well as the availability of transportation can play a significant barrier to registration of births.¹⁶ For example, in some countries children who live in urban areas are estimated to be six times more likely than those who live in rural areas to be registered.¹⁷ The Committee on the Rights of Persons with Disabilities (CRPD Committee) has frequently expressed concerns about the lack of registration of children with disabilities at birth. For instance, the CRPD Committee noted in its concluding observation on Paraguay that children with disabilities are not registered at birth especially in rural areas. Financial barriers, such as high fees to register a child’s birth, can prevent parents from doing so. Studies indicate that children from rich families are at least twice as likely to be registered as children from poor families.¹⁸

Further, in some countries legal barriers serve as an additional obstacle that prevents the registration of children with disabilities. For instance, a discriminatory law in Uganda limits the ability of people with disabilities to obtain dual citizenship with Uganda, which the CRPD Committee acknowledged as a discriminatory barrier to birth registration in the country.¹⁹

The largest barrier to birth registration for children with disabilities, however, stems from cultural prejudices, stigma, and shame associated with the birth of a disabled child, as parents can be reluctant or unwilling to register the birth of their disabled child.²⁰ For these same reasons, girls with disabilities are also at a heightened risk of infanticide. As the CRPD Committee notes in its General Comment No. 3 on women and girls with disabilities, girls with disabilities are particularly susceptible to infanticide, “because their families are unwilling or lack the support to raise a girl with an impairment.”²¹ UNICEF has further found that children with disabilities may be subjected to infanticide at birth or at some point

after birth because communities may consider these children to be evil or because families with children with disabilities can face intense stigma.²² UNICEF found that infanticide may also result from a family's wish to end the perceived suffering of a child with a disability, often referred to as a "mercy killing."²³ Acknowledging that the lack of birth registration leads to the invisibility of children with disabilities, the CRPD Committee notes that, absent any official record of their existence, "their death may occur with relative impunity."²⁴ In these situations, children with disabilities often stay invisible, without access to health care, education, and the other rights that accompany citizenship, including the right to life.²⁵

Birth registration and gender discrimination

While recent available data suggests a gender parity in birth registration and that birth registration rates between girls and boys, generally, are almost equivalent,²⁶ the absence of data disaggregated by gender and disability makes it quite difficult to determine if there is a gap in the rates of birth registration between girls and boys with disabilities. However, it is well established that girls with disabilities suffer multiple forms of discrimination due to their gender and disability.²⁷ As such, girls with disabilities might be less likely than boys with disabilities to have their birth registered, especially when taking into consideration other barriers that prevent the birth registration of children with disabilities in general. Recent concluding observations by the CRPD Committee to Gabon, for instance, support the possibility of a gender imbalance in birth registration, as the CRPD Committee expressed concern about the absence of data of birth registration of girls with disabilities.²⁸

Gender discrimination in birth registration can manifest in other ways as well. For example, laws requiring the presence of the father or the most senior male member in the family to register the child discriminate against the mother and prevent the registration of children who are born as a result of rape or out of wedlock.²⁹ Additionally, some countries' laws discriminate against the mother by preventing her from conferring her nationality to her child, which can lead to statelessness for children whose fathers refuse to acknowledge them.³⁰

Birth Registration in Emergency Situations

In emergency situations, unregistered children are exposed to greater risks including, but not limited to, statelessness, physical abuse, neglect, sexual exploitation, discrimination and gender-based violence.³¹ In emergency situations like armed conflicts or natural disasters, parents face multiple challenges to register the birth of their children.³² The disruption of civil registration systems, or inaccessibility of registration offices can prevent families from registering their children.³³ Emergency settings can also exacerbate other barriers including excessive fees³⁴ and lack of access to certain documents, such as birth records or marriage certificates, that are necessary to register children's births.³⁵ For instance, many Syrian refugees in Lebanon had to go back to Syria to either obtain civil documents to register their children.³⁶ In some instances, pregnant women traveled back to Syria to give birth due to the complex birth registration requirements as a refugee in Lebanon.³⁷ Moreover, in times of armed conflicts parents may also fear persecution, ethnic, cultural or religious discrimination which makes them more reluctant to register their children at birth.³⁸ In addition, lack of knowledge of the registration process or the importance of birth registration serves as an additional barrier to birth registration in these situations.³⁹

Challenges facing children with disabilities to have their birth registered can be exacerbated in emergency situations. The CRPD Committee has expressed concerns about the low rates of birth registration of children with disabilities in displacement situations or those who live in refugee camps.⁴⁰

The vulnerabilities linked to a failure to register the births of children with disabilities can also be exacerbated in emergency settings, as children with disabilities are at heightened risk of abandonment and exclusion from humanitarian assistance.⁴¹ Girls with disabilities are at particular risk in emergency

situations and more often subject to multiple forms of discrimination and abuse. Refugee and internally displaced girls with disabilities are also more likely than boys with disabilities to be subject to sexual abuse, neglect, and exploitation.⁴² As discussed above, the invisibility of children with disabilities whose births have not been registered can lead to impunity for the rights violations they experience, including gender-based violence.⁴³

II. Lack of birth registration violates fundamental rights for children with disabilities

All children have a right to have their births registered

Birth registration is a fundamental and universal human right for all children. It is protected in a number of core international human rights treaties, including the International Covenant on Civil and Political Rights (ICCPR),⁴⁴ the Convention on the Rights of the Child (CRC),⁴⁵ and the International Convention on the Protection of the Rights of all Migrant Workers and Members of their Families.⁴⁶ The CRC, in particular, requires state parties to register all children immediately after birth and recognizes the right of every child to a name and nationality from birth. Article 18 of the Convention on the Rights of Persons with Disabilities (CRPD) reinforces this obligation, requiring States in particular to register all children with disabilities immediately following their birth, and affirms the right of children with disabilities to have a name and to acquire a nationality.⁴⁷

Treaty bodies charged with monitoring State compliance with these treaties have offered guidance to States on how to give full effect to the right of all children to birth registration. The CRPD Committee in particular has made recommendations to States to promote the registration of children with disabilities on an equal basis as children without disabilities,⁴⁸ including recommending in at least one instance that registry procedures be decentralized to ensure better access for people living in rural areas and to make the process simple, quick, and free of charge.⁴⁹ The CRPD Committee has further called for the elimination of discriminatory laws that restrict access to citizenship for people with certain disabilities.⁵⁰ In several instances, the CRC Committee has called on States to raise awareness about the importance of birth registration and the fulfilment of all children's rights.⁵¹

With respect to emergency settings, the CRPD Committee has called on at least one State to strengthen and allocate sufficient resources to its registration programs to ensure the registration of children with disabilities in refugee camps and to ensure the access to necessary identity documents.⁵² Similarly, the CRC Committee called for creating an accessible and free registration program, including establishing mobile units in rural areas to ensure the registration of all displaced and refugee children.⁵³

Birth registration is essential to the full realization of other fundamental human rights

The right to birth registration is not only a fundamental right in and of itself, but it is inextricably linked to children's fulfillment of other fundamental rights, including their right to nationality, health, social services and education.⁵⁴ Given the heightened risk of institutionalization for children with disabilities whose births are not registered, as discussed above, birth registration also implicates the right of children with disabilities to live in the community.⁵⁵ The CRPD Committee's General Comment No. 1 highlights the serious consequences of non-registration on children with disabilities, including their inability to obtain citizenship and the denial of access to health care and education.⁵⁶ In its General Comment No. 9, the CRC Committee similarly notes that children with disabilities are "disproportionately vulnerable to non-registration at birth," which can put them in a great danger and prevent them from accessing vital human rights like the right to nationality, education and health care.⁵⁷

In emergency situations, States have even greater responsibility to ensure the birth registration of children with disabilities. The CRC Committee, in its General Comment No. 9, emphasizes that States must pay

specific attention to internally displaced children with disabilities during armed conflicts and natural disasters,⁵⁸ noting that displaced girls with disabilities are particularly vulnerable to various forms of abuse, neglect, and exploitation.⁵⁹

III. Recommendations and good practices:

In order to achieve a universal birth registration in implementing SDG Target 16.9, States should specifically create inclusive procedures to facilitate the birth registration of all children, including children with disabilities. To that end, States should:

- **Raise awareness among parents, government officials, religious leaders and medical personnel about the importance of birth registration for children with disabilities** and the role it plays in the fulfilment of their other rights. For example, Benin implemented changes to the civil registration system along with a mass public awareness campaign, which led to a 20 percent increase in the level of birth registration in the country in less than 6 years.⁶⁰ Relatedly, States must take steps to combat stigma and discrimination against children with disabilities and raise awareness about their rights more broadly.
- Ensure that all **information about birth registration is accessible and available** in alternative formats and multiple languages to ensure that parents with disabilities have access to this information.
- **Increase the number of registration facilities and consider innovative approaches to reach families in rural areas and refugee camps**, for instance by setting up mobile registration units and creating an online registration system. South Africa witnessed a rise from 24 percent of births being registered in 1991 to 95 percent of births being registered in 2012 due to the creation of new registration points and mobile units to increase the rate of birth registration in rural areas.⁶¹ Similarly, Namibia, with the support of UNICEF, established annual mobile registration campaigns in order to reach families in the most remote areas. This initiative, along with the establishment of new registration points in hospitals, led to a rise in the percentage of children under five with a birth certificate to reach 78 per cent in 2011 after it was 60 per cent in 2006.⁶²
- **Eliminate discriminatory laws, policies, and practices that restrict the registration of births of children with disabilities** or prevent them from obtaining nationality on an equal basis with children without disabilities.
- **Monitor and collect disaggregated data of birth registration rates**, including on the basis of both sex and disability.
- **Make birth registration free** and eliminate late fees for birth registration (or allow fee waivers for low income families). The births registration in Senegal increased by 20 percent between 2005 and 2010-2011, due in large part to the reduction of birth registration fees combined with mass awareness campaigns.⁶³
- **Simplify the birth registration process** and eliminate any administrative barriers that prevent parents from registering their disabled child at birth.

Thank you for your time and attention to this submission. Should you have any questions or require further information, please feel free to contact WEI at the email addresses provided below.

Stephanie Ortoleva, President and Legal Director (president@womenenabled.org)

Suzannah Phillips, Senior Legal Advisor (S.Phillips@womenenabled.org)

Khawla Wakkaf, Legal Fellow (k.wakkaf@womenenabled.org)

¹ United Nations General Assembly, *Transforming Our World: the 2030 Agenda for Sustainable Development*, Target 16.9, U.N. Doc. A/RES/70/1 (2015).

² UNICEF, EVERY CHILD’S BIRTH RIGHT: INEQUITIES AND TRENDS IN BIRTH REGISTRATION 14 (2013), *available at* https://data.unicef.org/wp-content/uploads/2015/12/Birth_Registration_lores_final_24.pdf [hereinafter EVERY CHILD’S BIRTH RIGHT]

³ *Id.*, at 14, 16.

⁴ *Id.*, at 16.

⁵ Convention on the Rights of Persons with Disabilities, art. 31, G.A. Res. 61/106, U.N. Doc. A/RES/61/106 (Dec. 13, 2006), *available at* <http://www.unhcr.org/refworld/docid/45f973632.html> [hereinafter CRPD].

⁶ World Health Organization (WHO), *Disability and Health* (Nov. 2016), *available at* <http://www.who.int/mediacentre/factsheets/fs352/en/>.

⁷ WHO & WORLD BANK, WORLD REPORT ON DISABILITY, Table 2.1 (2011), *available at* <http://documents.worldbank.org/curated/en/2011/01/14440066/world-report-disability>.

⁸ UNICEF, *Fact Sheet: Children and Young People with Disabilities* 10 (2013), *available at* https://www.unicef.org/disabilities/files/Factsheet_A5_Web_NEW.pdf [hereinafter Children and Young People with Disabilities].

⁹ UNICEF, A PASSPORT TO PROTECTION: A GUIDE TO BIRTH REGISTRATION PROGRAMMING 11, 12 (2013), *available at* https://www.unicef.org/protection/files/UNICEF_Birth_Registration_Handbook.pdf [hereinafter A PASSPORT TO PROTECTION].

¹⁰ *Id.*

¹¹ Committee on the Rights of the Child (CRC Committee), *General comment No. 9: The rights of children with disabilities*, ¶ 35, U.N. Doc. CRC/C/GC/9 27 (2007). *See also*, Marianne Schulze, Understanding The UN Convention on the Rights of Persons with Disabilities, 49, 65, 77, (2009), *available at* https://iddeconsortium.net/sites/default/files/resources-tools/files/hi_crpdc_manual_sept2009_final.pdf.

¹² CRC Committee, *General Comment No. 9*, *supra* note 11, ¶ 35. *See also*, WHO & FUNDAÇÃO CALOUSTE GULBENKIAN, PROMOTING RIGHTS AND COMMUNITY LIVING FOR CHILDREN WITH PSYCHOSOCIAL DISABILITIES 15, 16 (2015), *available at* http://apps.who.int/iris/bitstream/10665/184033/1/9789241565004_eng.pdf.

¹³ CRC Committee, *Concluding Observations: Albania*, ¶ (H)(c), U.N. Doc. CRC/C/ALB/CO/2-4 (2012).

¹⁴ PLAN INTERNATIONAL, BIRTH REGISTRATION IN EMERGENCIES: A REVIEW OF BEST PRACTICES IN HUMANITARIAN ACTION 10, 11 (2014), *available at* <https://www.planusa.org/docs/reports/2014-Birth-Registration-in-Emergencies.pdf>.

¹⁵ CRC Committee, *General Comment No. 9*, *supra* note 11, ¶ 35; UNICEF, THE STATE OF THE WORLD’S CHILDREN 2013: CHILDREN WITH DISABILITIES 41 (2013), *available at* http://www.unicef.org/publications/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf.

¹⁶ EVERY CHILD’S BIRTH RIGHT, *supra* note 2, at 23.

¹⁷ *Id.*, at 26, 27.

¹⁸ *Id.*, at 22, 23, 28.

¹⁹ Committee on the Rights of Persons with Disabilities (CRPD Committee), *Concluding observations: Uganda*, ¶¶ 36-37, UN Doc CRPD/C/UGA/CO/1 (2016).

²⁰ UNICEF, PROMOTING THE RIGHTS OF CHILDREN WITH DISABILITIES 4, 14 (2007), *available at* http://www.un.org/esa/socdev/nyin/documents/children_disability_rights.pdf. *See also*, UN General Assembly, *Birth registration and the right of everyone to recognition everywhere as a person before the law*, ¶ 68, U.N. Doc. A/HRC/27/22 (2014) [hereinafter *Birth Registration*].

²¹ CRPD Committee, *General Comment No. 3: Women and girls with disabilities*, ¶ 36, U.N. Doc. CRPD/C/GC/3 (2016).

²² UNICEF Thematic Group on Violence against Disabled Children, *Summary Report: Violence against Disabled Children 6* (2005), *available at* https://www.unicef.org/videoaudio/PDFs/UNICEF_Violence_Against_Disabled_Children_Report_Distributed_Version.pdf.

²³ *Id.*, at 6.

²⁴ CRPD Committee, *General Comment No. 1: Equal recognition before the law*, ¶ 43, U.N. Doc. CRPD/C/GC/1 (2014).

²⁵ PROMOTING THE RIGHTS OF CHILDREN WITH DISABILITIES, *supra* note 20, at 4, 14; *Birth Registration*, *supra* note 20, ¶ 68.

²⁶ EVERY CHILD’S BIRTH RIGHT, *supra* note 2, at 22, 24.

²⁷ CRPD Committee, *General comment No. 3*, *supra* note 21, ¶¶ 2,3,17.

²⁸ CRPD Committee, *Concluding Observations: Gabon*, ¶¶ 42,43, U.N. Doc. CRPD/C/GAB/CO/1 (2015).

²⁹ *Birth Registration*, *supra* note 20, ¶ 69.

³⁰ *Id.*, ¶ 70.

³¹ PLAN INTERNATIONAL, *supra* note 14, at 6, 12. *See also*, A PASSPORT TO PROTECTION, *supra* note 9, at 42, 47.

³² PLAN INTERNATIONAL, *supra* note 14, at 13, 14.

³³ *Id.*, at 14, 2014. *See also*, *Birth Registration*, *supra* note 20, ¶¶ 71, 72.

³⁴ PLAN INTERNATIONAL, *supra* note 14, at 45.

³⁵ *Id.*, at 14, 2014. *See also*, UN High Commissioner for Refugees (UNHCR), *Protection of Refugee Children in the Middle East and North Africa* 16, 17 (Oct. 2014), *available at* <http://www.refworld.org/docid/54589a6a4.html%20>.

³⁶ UNHCR, *The Future of Syria: Refugee Children in Crisis* 11, 56 (2013), *available at* <http://www.refworld.org/docid/529c3b4d4.html>.

³⁷ *Id.*

³⁸ PLAN INTERNATIONAL, *supra* note 14, at 14.

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- ³⁹ A PASSPORT TO PROTECTION, *supra* note 9, at 103. *See also*, EVERY CHILD’S BIRTH RIGHT, *supra* note 2, at 20.
- ⁴⁰ CRPD Committee, *Concluding Observations: Kenya*, ¶¶ 35-36, U.N. Doc. CRPD/C/KEN/CO/1(2015).
- ⁴¹ CRC Committee, *General Comment No. 9*, *supra* note 11, ¶ 79; UNICEF & HANDICAP INTERNATIONAL, GUIDANCE INCLUDING CHILDREN WITH DISABILITIES IN HUMANITARIAN ACTION 6 (2017), *available at* https://reliefweb.int/sites/reliefweb.int/files/resources/General_Guidance_English_2017.pdf; THE STATE OF THE WORLD’S CHILDREN 2013, *supra* note 15, at 52.
- ⁴² CRC Committee, *General Comment No. 9*, *supra* note 11, ¶ 79.
- ⁴³ CRPD Committee, *General Comment No. 1*, *supra* note 24, ¶ 43.
- ⁴⁴ International Covenant on Civil and Political Rights, *adopted* Dec. 16, 1966, art. 24(2), G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976).
- ⁴⁵ Convention on the Rights of the Child, *adopted* Nov. 20, 1989, arts. 7, 8, G.A. Res. 44/25, annex, U.N. GAOR, 44th Sess., Supp. No. 49, U.N. Doc. A/44/49 (1989) (*entered into force* Sept. 2, 1990).
- ⁴⁶ International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, *adopted* Dec. 18, 1990, art. 29, G.A. Res. 45/158, annex, 45 U.N. GAOR Supp. (No. 49A) at 262, UN Doc. A/45/49 (1990) (*entered into force* July 1, 2003).
- ⁴⁷ CRPD, *supra* note 5, art. 18.
- ⁴⁸ *See, e.g.*, CRPD Committee, *Concluding Observations: Gabon*, ¶¶ 42-43, U.N. Doc. CRPD/C/GAB/CO/1 (2015); CRPD Committee, *Concluding Observations: Paraguay*, ¶ 46, U.N. Doc. CRPD/C/PRY/CO/1 (2013).
- ⁴⁹ CRPD Committee, *Concluding Observations: Paraguay*, ¶ 46, U.N. Doc. CRPD/C/PRY/CO/1 (2013).
- ⁵⁰ CRPD Committee, *Concluding observations: Uganda*, ¶¶ 36-37, UN Doc CRPD/C/UGA/CO/1 (2016).
- ⁵¹ CRC Committee, *Concluding Observations: Burundi* ¶ 38 (C), U.N. Doc. CRC/C/BDI/CO/2 (2010). *See also*, CRC Committee, *Concluding Observations: India* ¶ (C), U.N. Doc. CRC/C/IND/CO/3-4 (2014).
- ⁵² CRPD Committee, *Concluding Observations: Kenya*, ¶ 36, U.N. Doc. CRPD/C/KEN/CO/1(2015).
- ⁵³ CRC Committee, *Concluding Observations: Burundi*, ¶ 38, U.N. Doc. CRC/C/BDI/CO/2 (2010).
- ⁵⁴ *Birth Registration*, *supra* note 20, ¶ 11.
- ⁵⁵ CRPD, *supra* note 5, arts.18 (2), 19.
- ⁵⁶ CRPD Committee, *General Comment No. 1*, *supra* note 24, ¶ 43.
- ⁵⁷ CRC Committee, *General Comment No. 9*, *supra* note 11, ¶ 35.
- ⁵⁸ *Id.*, ¶ 79.
- ⁵⁹ *Id.*
- ⁶⁰ EVERY CHILD’S BIRTH RIGHT, *supra* note 2, at 32.
- ⁶¹ *Id.*
- ⁶² *Id.*
- ⁶³ *Id.*, at 33.