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**IN THE HIGH COURT OF SOUTH AFRICA
(WESTERN CAPE HIGH COURT, CAPE TOWN)**

Case no 18678/07

In the matter between:

**WESTERN CAPE FORUM FOR INTELLECTUAL
DISABILITY**

Applicant

and

APPLICANT'S HEADS OF ARGUMENT

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INTRODUCTION

1. This application concerns the failure of the respondents to provide basic education for Western Cape children with severe or profound intellectual disabilities, in breach of their constitutional rights. The applicant is an association of organizations which care for such children. It asks that the respondents be ordered to take reasonable steps to rectify the infringement of the rights of the children concerned.
2. The respondents are the national and provincial governments. They do not take responsibility for the education of such children. Instead, they leave it to the members of the applicant, which are voluntary organizations which run special care centres, to provide these children with an education. The government provides a limited subsidy to those centres.
3. Such children therefore do not receive basic education unless they are fortunate enough to gain access to a special care centre which is willing and able to provide for them. There are insufficient special care centres to cater for all such children.
4. The special care centres provide education under conditions of severely constrained resources. The state provides the special care centres with a subsidy which is
 - 4.1. inadequate in relation to the educational needs of such children;
 - 4.2. less than the contribution which it makes to the education of children who are not so disabled.
5. The applicant contends that the policy and practice of the respondents infringe the rights of such children to a basic education, to equality, to dignity, and to be protected from neglect and degradation.
6. These heads of argument deal with the following matters:
 - 6.1. The facts
 - 6.2. The issues
 - 6.3. The right to a basic education
 - 6.4. The right to equality

- 6.5. The right to human dignity
- 6.6. The right to be protected from neglect and degradation
- 6.7. The respondents' defences
- 6.8. The relief sought

THE FACTS

7. The state establishes and funds schools. These include special schools, which cater for the needs of children who are classified as having moderate to mild intellectual disabilities (IQ levels of 35-70).¹
8. Children with an IQ under 35 are considered to be severely (20-35) or profoundly (less than 20) intellectually disabled.² They are not admitted to special schools,³ or to any other state schools.
9. The state makes no direct education provision for children with severe or profound intellectual disabilities. It does not provide any schools in the Western Cape for such children.⁴
10. In the Western Cape, the only education available for such children is at special care centres which are run by non-governmental organisations, such as the members of the applicant.⁵ This is common cause.⁶ Approximately 1000 of these children are cared for by members of the applicant at special care centres.⁷
11. If the children are not able to find a special care centre which is willing and able to admit them, they receive no education at all.⁸ This too is common cause. There are insufficient special care centres to cater for all such children.⁹
12. The only contribution which the state makes to the education of such children is a subsidy, through the Department of Health, to the organisations which provide this service.¹⁰
13. This financial support is wholly inadequate.¹¹ It is also less than the state provides for the education of children who are not so disabled. In the Western Cape

¹ Shaboodien vol 1 p 9 para 9; Tyobeka vol 2 p 151 para 11.3.

² See Shaboodien vol 1 p 72 FS7 for the classification of intellectual disability.

³ Shaboodien vol 1 p 10 para 10; Tyobeka vol 2 p 151 para 11.3; Shaboodien vol 6 p 2027

FS10.

⁴ Shaboodien vol 1 p 14 para 18; Theron vol 3 p 815 para 45.3.

⁵ Shaboodien vol 1 p 14 para 19.

⁶ Tyobeka vol 2 p 154 para 13.3, Theron vol 3 p 815 para 45.2.

⁷ Shaboodien vol 1 p 14 para 20.

⁸ Shaboodien vol 1 p 14 para 21.

⁹ Molteno vol 1 p 100 para 26.3.

¹⁰ Shaboodien vol 1 p 10 para; Tyobeka vol 2 p 151 para 11.3.

¹¹ Shaboodien vol 1 p 10 para 11.

- 13.1. the respondents (through the Department of Health) pay an annual subsidy of R5 092.20 per child for children with severe or profound intellectual disabilities who attend special care centres.¹²
- 13.2. the respondents spend R6 632.00 per child per annum on children who attend mainstream schools.¹³
- 13.3. the respondents spend R26 767.00 per child per annum on children with mild to moderate intellectual disabilities who attend special schools.¹⁴
14. Children with severe or profound intellectual disabilities are able to benefit from education and training.¹⁵ This is accepted by the respondents,¹⁶ and has long been internationally accepted.¹⁷
15. Such children have needs which are very much greater than those of children who do not have this degree of disability. The majority of the children in question have secondary disabilities such as epilepsy, visual and hearing impairment and cerebral palsy.¹⁸
16. The state provision for children with severe or profound intellectual disabilities is therefore
- 16.1. very much less than is provided for other children;
- 16.2. inadequate to cater for the educational needs of these children; and
- 16.3. only made available where a non-governmental organisation provides such facilities.

¹² Shaboodien vol 6 p 1980 para 11.4. The subsidy has been increased to R6 049.68 per child per annum with effect from April 2009: footnote 17 record p1980. The earlier figure is, however appropriate for the purposes of comparison with the subsidies for children not so disabled, as the only figures available in that regard are those for 2006/2007. See in this regard paragraphs 5 and 7 Record p2043.

¹³ Shaboodien vol 6 p 1981 para 11.7.

¹⁴ Shaboodien vol 6 p 1981 para 11.7.

¹⁵ See, in this regard, the affidavit of Professor Molteno vol 1 p 88.

¹⁶ Theron vol 3 p 818 para 51; Cupido Shaboodien vol 1 p para vol 5 p 1433 para 44.

¹⁷ Molteno vol 1 pp90-93 paras 7-13.

¹⁸ Shaboodien vol 1 p 15 para 26; Molteno vol 1 p 101 para 28.

THE ISSUES

17. The applicant contends that the policy and practice of the respondents infringe the rights of children with severe or profound intellectual disabilities.

The right to education

18. First, they infringe the right of such children to a basic education, contained in section 29(1)(a) of the Constitution:

18.1. In many cases, the children receive no education at all.

18.2. In those cases in which education is provided by a special care centre, the subsidy which is provided is wholly inadequate to provide the education which the children require.

The right to equality

19. Second, they infringe the right of such children to equality, in terms of section 9 of the Constitution. They discriminate unfairly against these children on the grounds of their degree of intellectual disability.
20. Children with severe or profound intellectual disabilities constitute a particularly vulnerable and marginalised group. The policy and practice of the respondents unfairly discriminate against these children, because

20.1. While the state has established and funded schools for other children, it has not done so for children who are severely or profoundly intellectually disabled. All it provides is a subsidy towards the running costs of non-governmental organisations which have decided to establish and conduct such schools.

20.2. Children who are not so disabled have a right to attend a school which is suitable for them. The state fulfils that right. The state accepts the obligation to establish enough schools to ensure that every child may enjoy that right. By contrast, children who are so disabled are not able to enjoy that right unless they are fortunate enough to find a school which is conducted by a non-governmental organisation, and which is willing and able to accept them. The state does not accept the obligation to ensure that every such child is able to attend an appropriate school.

20.3. The state's contribution to the education of these children is unequal in absolute terms, in that it is substantially less than the amount which the state contributes to the education of children who do not have such disabilities.

20.4. The state's contribution to the education of these children is substantively unequal. The state provides for the educational needs of children who are not so disabled with due regard to their actual needs. However, its provision for these disabled children has no regard to and does not provide for their actual needs, which are in fact greater.

The right to human dignity

21. Third, they infringe the right of such children to human dignity, in terms of section 10 of the Constitution. The children are treated as unworthy of a basic education, and are not given the opportunity to develop their full potential. They are thus denied the opportunity to develop a sense of self-worth and human dignity.

The right to protection from neglect and degradation

22. Fourth, they infringe the right of such children to protection from neglect and degradation, to which they are entitled in terms of section 28(1)(d) of the Constitution, in that they fail to provide the children with the training and skills which they need.

23. We deal with each of these rights in turn.

THE RIGHT TO A BASIC EDUCATION

24. Section 29 of the Constitution provides as follows:

29 Education

(1) *Everyone has the right-*

(a) to a basic education...

25. Education has been described as an “*empowerment right*”, in that it facilitates the enjoyment of other constitutional rights.¹⁹ This aspect of the right was recognised in Minister of Home Affairs and others v Watchenuka and another,²⁰ where the court emphasised the importance of the right to a basic education for human dignity and for “*human fulfilment at a critical period*”.
26. Section 7(2) of the Constitution states that the state must “*respect, protect, promote and fulfil*” the rights in the Bill of Rights.
27. The duty to ‘fulfil’ a right means that the state must take measures to assist people to enjoy the right. It requires the state to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures towards the full realisation of the right. Where individuals are unable, for reasons beyond their control, to enjoy the right by means at their own disposal, the state has an obligation to fulfil or provide that right directly.²¹ The right to a basic education in section 29 of the Constitution thus obliges the state to provide a basic education.
28. This was recognised by the Constitutional Court in Ex Parte Gauteng Provincial Legislature: In re dispute concerning the constitutionality of certain provisions of the Gauteng School Education Bill of 1995.²² The Constitutional Court stated (referring to the Interim Constitution) that

¹⁹ S. Woolman and B. Fleisch The Constitution in the Classroom (2009) Pretoria University Law Press at pp117-118.

²⁰ 2004 (4) SA 326 (SCA) at para [36]

²¹ United Nations Committee on Economic, Social and Cultural Rights General Comment No 12, ‘The right to adequate food’, E/C. 12/1999/5, para 15; General Comment No 14, ‘The right to the highest attainable standard of health’, E/C. 12/2000/4, para 33.

²² 1996 (3) SA 165 (CC)

"[9]... Section 32(a) creates a positive right that basic education be provided for every person and not merely a negative right that such a person should not be obstructed in pursuing his or her basic education."

29. In this case, the respondents are infringing both the positive dimension of the right - by failing to provide such children with a basic education - and the negative dimension of the right, by not admitting the children concerned to special or other schools.
30. This obligation is specifically addressed by a number of international instruments. Adjudicatory bodies have consistently stated the obligation of the state to provide education for children such as these.
31. The United Nations Convention on the Rights of the Child states in Article 23 that *"a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community."* Article 28 confirms the right to education. Article 29(1)(a) states that *"the education of the child shall be directed to... [t]he development of the child's personality, talents and mental and physical abilities to their fullest potential"*.
32. The African Charter on the Rights and Welfare of the Child provides in Article 11(1) and (2)(a) that *"[e]very child shall have the right to an education"* and the *"[t]he education of the child shall be directed to... the promotion and development of the child's personality, talents and mental and physical abilities to their fullest potential..."* Article 13 provides:

"1. Every child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity, promote his self-reliance and active participation in the community."

2. States Parties to the present Charter shall ensure, subject to available resources, to a disabled child and to those responsible for his care, of assistance for which application is made and which is appropriate to the child's condition and in particular shall ensure that the disabled child has effective access to training, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration, individual development and his cultural and moral development."

33. Article 15 of the Revised European Social Charter provides for the right of persons with disabilities to independence, social integration and participation in the life of the community, and recognises the importance of education for those purposes. Article 17 provides for the right of children and young persons to social, legal and economic protection as follows:

“With a view to ensuring the effective exercise of the right of children and young persons to grow up in an environment which encourages the full development of their personality and of their physical and mental capacities, the Parties undertake, either directly or in co-operation with public and private organisations, to take all appropriate and necessary measures designed:

1. a to ensure that children and young persons, taking account of the rights and duties of their parents, have the care, the assistance, the education and the training they need, in particular by providing for the establishment or maintenance of institutions and services sufficient and adequate for this purpose;...”

34. In the matter of Autism-Europe v France²³ the adjudicatory body on the Charter, the European Committee of Social Rights, held as follows in a complaint based on these Articles:

“... the Committee views Article 15 of the Revised Charter as both reflecting and advancing a profound shift of values in all European countries over the past decade away from treating them as objects of pity and towards respecting them as equal citizens... The underlying vision of Article 15 is one of equal citizenship for persons with disabilities and, fittingly, the primary rights are those of ‘independence, social integration and participation in the life of the community’. Securing a right to education for children and others with disabilities plays an obviously important role in advancing these citizenship rights. This explains why education is now specifically mentioned in the revised Article 15 and why such an emphasis is placed on achieving that education ‘in the framework of general schemes, wherever possible’. It should be noted that Article 15 applies to all persons with disabilities regardless of the nature and origin of their disability and irrespective of their age...”

35. In that case, the Committee held that France had failed to achieve sufficient progress in advancing the provision of education for persons with autism, in that it had failed to ensure sufficient places in formal educational institutions.

²³ Complaint No.13/2002

36. Article 13 of the International Covenant on Economic, Social and Cultural Rights entrenches the right to education. In General Comment 13, the UN Committee on Economic, Social and Cultural Rights (CESCR) explained this as follows:

“Education is both a human right in itself and an indispensable means of realizing other human rights. As an empowerment right, education is the primary vehicle by which economically and socially marginalized adults and children can lift themselves out of poverty and obtain the means to participate fully in their communities.”

37. The Convention on the Rights of Persons with Disabilities and its Optional Protocol were ratified by South Africa on 30 November 2007. It deals very specifically with this matter, and we therefore quote it at some length.

38. The Preamble of the Convention provides as follows:

“(m) Recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities, and that the promotion of the full enjoyment by persons with disabilities of their human rights and fundamental freedoms and of full participation by persons with disabilities will result in their enhanced sense of belonging and in significant advances in the human, social and economic development of society and the eradication of poverty,..

(r) Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child...

39. Article 24 of the Convention provides as follows:

“1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:

(a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;

(b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;

(c) Enabling persons with disabilities to participate effectively in a free society.

2. In realizing this right, States Parties shall ensure that:

(a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

(b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

(c) Reasonable accommodation of the individual's requirements is provided;

(d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

(e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures...

4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities."

40. The Convention and the other international instruments place the responsibility for the provision of education to disabled children squarely on the state - as, of course, the Constitution does. While the state may choose to co-operate with non-governmental organisations in providing this education, this does not shift the constitutional obligation away from the government and onto the nongovernmental organizations. In President of the Republic of South Africa and another v Modderklip Boerdery (Pty) Ltd (Agri SA and others, Amici Curiae)²⁴ the Constitutional Court held as follows:

"[45] ...It is unreasonable for a private entity such as Modderklip to be forced to bear the burden which should be borne by the State, of providing the occupiers with accommodation..."

41. The very matter in issue in this case – the failure of the government to provide education for intellectually handicapped children - was considered in the Irish High Court in the O'Donoghue case.²⁵ The court dealt as follows with the right to basic education ("primary education" in the context of the Irish Constitution) in respect of intellectually handicapped children:

"I conclude, having regard to what has gone before, that there is a constitutional obligation imposed on the State by the provisions of Article 42.4 of the Constitution to provide for free basic elementary education of all children and that this involves giving each child such advice, instruction and teaching as will enable him or her to make the best possible use of his or her inherent and potential capacities, physical, mental and moral, however limited these capacities may be. Or, to borrow the language of the United Nations Convention and Resolution of the General Assembly -- "such education as will be conducive to the child's achieving the fullest possible social integration and individual development; such education as will enable the child to develop his or her capabilities and skills to the maximum and will hasten the process of social integration and reintegration".

This process will work differently for each child, according to the child's own natural gifts, or lack thereof. In the case of the child who is deaf, dumb, blind, or otherwise physically or mentally

²⁴ 2005 (5) SA 3 (CC)

²⁵ O'Donoghue (a Minor) suing by his mother and next friend O'Donoghue v The Minister for Health, The Minister for Education, Ireland and the Attorney General. [1993] IEHC 2; [1996] 2 IR 20 (27th May, 1993). This judgment was approved by the Irish Supreme Court in Sinnott v. Minister for Education [2001] IESC 63; [2001] 2 IR 505 (12 July 2001).

handicapped, a completely different programme of education has to be adopted and a completely different rate of progress has to be taken for granted, than would be regarded as appropriate for a child suffering from no such handicap."

42. The High Court held that the failure of the government to provide such education for intellectually disabled children was in breach of the Constitution.
43. This approach is consonant with that of the international instruments to which we have referred above. In General Comment 13 of the CESCR, for example, the following "*interrelated and essential features*" of the education to be provided to all children were identified:

"(a) Availability - functioning educational institutions and programmes have to be available in sufficient quantity within the jurisdiction of the State party....;

(b) Accessibility - educational institutions and programmes have to be accessible to everyone, without discrimination, within the jurisdiction of the State party. Accessibility has three overlapping dimensions:

Non-discrimination - education must be accessible to all, especially the most vulnerable groups, in law and fact, without discrimination on any of the prohibited grounds...;

Physical accessibility - education has to be within safe physical reach ...;

Economic accessibility - education has to be affordable to all...

(c) Acceptability - the form and substance of education, including curricula and teaching methods, have to be acceptable (e.g. relevant, culturally appropriate and of good quality) ...

(d) Adaptability - education has to be flexible so it can adapt to the needs of changing societies and communities and respond to the needs of students within their diverse social and cultural settings.

7. When considering the appropriate application of these 'interrelated and essential features' the best interests of the student shall be a primary consideration."

44. The applicant's members endeavour to provide an education of this nature to the children at their special care centres. However, they are constrained by severely limited resources. For example, they are able only to provide very limited transport to children who attend the centres. This impacts on the accessibility of the education.²⁶

²⁶ Molteno vol 1 pp 95-96 paras 17-18.

THE RIGHT TO EQUALITY

45. Section 9 of the Constitution guarantees the right to equality. Disability is a specified ground of prohibited discrimination.
46. The Constitutional Court has frequently emphasised that the guarantee of equality "*lies at the very heart of the Constitution*" and "*permeates and defines the very ethos upon which the Constitution is premised*".²⁷
47. In President of the Republic of South Africa and another v Hugo²⁸ the Constitutional Court held as follows:

"[41] The prohibition on unfair discrimination in the interim Constitution seeks not only to avoid discrimination against people who are members of disadvantaged groups. It seeks more than that. At the heart of the prohibition of unfair discrimination lies a recognition that the purpose of our new constitutional and democratic order is the establishment of a society in which all human beings will be accorded equal dignity and respect regardless of their membership of particular groups. The achievement of such a society in the context of our deeply inegalitarian past will not be easy, but that that is the goal of the Constitution should not be forgotten or overlooked. In Egan v Canada [(1995) 29 CRR (2d) 79] L'Heureux-Dubé J analysed the purpose of s 15 of the Canadian Charter (which entrenches the right to equality) as follows:

'Equality, as that concept is enshrined as a fundamental human right within s 15 of the Charter means nothing if it does not represent a commitment to recognising each person's equal worth as a human being, regardless of individual differences. Equality means that our society cannot tolerate legislative distinctions that treat certain people as second-class citizens, that demean them, that treat them as less capable for no good reason, or that otherwise offend fundamental human dignity.'"

²⁷ Fraser v The Children's Court, Pretoria North 1997 (2) SA 261 (CC) para 20; Satchwell v President of the RSA 2002 (6) SA 1 (CC) para 18. See also Brink v Kitshoff NO 1996 (4) SA 197 (CC) para 33; Shabalala v AG Transvaal 1996 (1) SA 725 (CC) para 26; S v Makwanyane 1995 (3) SA 391 (CC) paras 155 to 166 and 262

²⁸ 1997 (4) SA 1 (CC)

48. South African equality jurisprudence was summarized in Geldenhuys v National Director of Public Prosecutions & Others²⁹, where the Constitutional Court held as follows:

"[29] It is now well-settled jurisprudence under the Constitution, that where an impugned provision differentiates between categories of people, it must bear a rational connection to a legitimate government purpose; otherwise the differentiation is in violation of s 9(1) of the Constitution.

[30] Further, if the differentiation is on a ground specified in s 9(3) of the Constitution, unfairness is presumed. Absent a rebuttal of the presumption, unfair discrimination is established, resulting in a violation of s 9(3) of the Constitution. The final step is to determine whether the violation is justified under the general limitations provision in s 36 of the Constitution." (footnotes omitted)

49. The policy and practice of the respondents with regard to the education of children with severe or profound intellectual disabilities clearly differentiates between categories of children on the grounds of their intellectual disability. Disability is a specified ground of prohibited discrimination. The differentiation is therefore presumed to be unfair. It amounts to constitutionally prohibited unfair discrimination unless this presumption has been rebutted.
50. The respondents have not attempted to show that the differentiation is fair. They have not, for example, suggested that children with severe or profound intellectual disabilities are uneducable, and that it is therefore not unfair to differentiate between them and children with lesser intellectual disabilities.
51. Any such claim would constitute a further assault on the dignity of the children concerned. It would also fly in the face of the undisputed evidence of Professor Molteno, a recognised expert in the field.³⁰ The weight of international research and opinion, as reflected in the international instruments, has also long discredited such a view. In the O'Donoghue case the court conducted an exhaustive investigation of the matter. The court held that, on the basis of a definition of education as *"the teaching and training of a child to make the best possible use of his inherent and potential capacities, physical, mental and moral"*, it is apparent that such children are indeed capable of benefiting from education. Indeed, the court held,

²⁹ 2009 (2) SA 310 (CC)

³⁰ Molteno vol 1 pp89-90 paras 3-4 and 7-8.

"[t]he whole momentum, as evidenced in the Declarations emanating from the Vatican, from the United Nations, and in the Protocol to the European Convention on Human Rights, has been towards the provision for every individual of such education as will enable him or her... 'to make the best possible use of his (or her) inherent and potential capacities, physical, mental and moral'... however limited those capacities may be".

52. The court held as follows:

"I conclude, having regard to what has gone before, that there is a constitutional obligation imposed on the State by the provisions of Article 42.4 of the Constitution to provide for free basic elementary education of all children..."

The State has hitherto responded generously to its obligations in relation to virtually all of these categories of handicapped children, as has been recognised in the Reports already referred to, but has clearly lagged behind many other developed countries in what has been undertaken on behalf of the small but most seriously handicapped group of all -- the category to which the Plaintiff in the present proceedings belongs [severely or profoundly intellectually disabled].

Admittedly, it is only in the last few decades that research into the problems of the severely and profoundly physically and mentally handicapped has led to positive findings that education in a formal setting, involving schools and teachers, educational equipment of many kinds, and integration as far as possible in the conventional school environment, can be of real benefit to children thus handicapped. But once that has been established -- and my conclusion is that it has been established on a world-wide basis for many years past, then it appears to me that it gives rise to a constitutional obligation on the part of the State to respond to such findings by providing for free primary education for this group of children in as full and positive a manner as it has done for all other children in the community."

53. Such children are manifestly members of a particularly vulnerable group, who have been victims of discrimination and disadvantage in the past. The respondents' failure to provide such children with a basic education, in breach of their constitutional right, entrenches and exacerbates their disadvantage and impairs their human dignity and self-worth.

THE RIGHT TO HUMAN DIGNITY

54. Section 10 of the Constitution provides as follows:

10 Human dignity

Everyone has inherent dignity and the right to have their dignity respected and protected.

55. Our courts have frequently emphasised the importance of dignity as both a founding value and an enforceable right under the Constitution. O'Regan J for instance said in Dawood³¹ that:

"The value of dignity in our Constitutional framework cannot therefore be doubted. The Constitution asserts dignity to contradict our past in which human dignity for black South Africans was routinely and cruelly denied. It asserts it too, to inform the future, to invest in our democracy respect for the intrinsic worth of all human beings. Human dignity therefore informs constitutional adjudication and interpretation at a range of levels. It is a value that informs the interpretation of many, possibly all, other rights. This Court has already acknowledged the importance of the constitutional value of dignity in interpreting rights such as the right to equality, the right not to be punished in a cruel, inhuman or degrading way, and the right to life. Human dignity is also a constitutional value that is of central significance in the limitations analysis. Section 10, however, makes it plain that dignity is not only a value fundamental to our Constitution, it is a justiciable and enforceable right that must be respected and protected."

56. In the Law case³² in the Supreme Court of Canada, Iacobucci J described the concept of human dignity as follows:

"Human dignity means that an individual or group feels self-respect and self-worth. It is concerned with physical and psychological integrity and empowerment... Human dignity is harmed when individuals and groups are marginalised, ignored, or devalued, and

³¹ Dawood v Minister of Home Affairs 2000 (3) SA 936 (CC) para 35. See also Khumalo v Holomisa 2002 (5) SA 401 (CC) para 26

³² Law v Canada (1999) 60 CRR (2d) 1 (SCC) 22. This was cited with approval by the Constitutional Court in National Coalition for Gay and Lesbian Equality and others v Minister of Home Affairs and others 2000 (2) SA 1 (CC) para [41], note 50

is enhanced when laws recognize the full place of all individuals and groups within Canadian society."

57. To treat children with severe or profound intellectual disabilities as unworthy of state-provided education, devalues them. To do so serves to stigmatise an already vulnerable group of children. The failure to provide such children with a basic education robs them of the opportunity to develop a sense of self-worth and dignity, which they can only do if they are permitted to develop their potential to the full.

THE RIGHT TO BE PROTECTED FROM NEGLECT AND DEGRADATION

58. Section 28 of the Constitution provides as follows:

"28 Children

(1) Every child has the right-

...

(d) to be protected from maltreatment, neglect, abuse or degradation;

(2) A child's best interests are of paramount importance in every matter concerning the child."

59. The respondents' failure to provide for the education of the children concerned places them at risk of neglect and degradation. As pointed out above, education serves an empowerment function. It provides children with a sense of dignity and self-worth.
60. The respondents' failure to provide for the education of these children means, in practice, that such children often have to be educated by parents who do not have the skills to do so, and who are already under considerable strain. It is a form of neglect.
61. A lack of education results in the inability of such children to develop their potential, which in itself is a form of degradation.

THE RESPONDENTS' DEFENCES

62. The respondents deny that their policies infringe the rights of children with severe or profound intellectual disabilities. They have filed a very large volume of paper, most of which is not relevant to any matter which the Court is called upon to decide. The respondents' answer to the application, and the applicant's response, may be conveniently summarised under five headings.
- (1) **'Legislation and policy do not discriminate on the grounds of disability'**

63. The respondents say that there is no legislation or policy that excludes learners from state schools on the grounds of the severity of their intellectual disability.³³
64. The respondents admit that special schools only accommodate learners who have mild to moderate intellectual disabilities.³⁴ They say that this is not done in terms of legislation or policy. This is however irrelevant. As a matter of fact, which is common cause, children with severe or profound intellectual disabilities are excluded from special schools.³⁵

³³ Tyobeka vol 2 p 148 para 7.

³⁴ Tyobeka p 151 para 11.3.

³⁵ See for example letters from one such special school requesting a special care centre to admit children, whom the special school cannot admit because of the severity of their intellectual disability (Shaboodien vol 6 pp 2027-2030 FS10).

(2) 'Future policy will in any event eradicate such discrimination'

65. The respondents say that their objective is to ensure, at an unspecified time in the future, that such children are catered for by special schools.³⁶
66. This is no defence: the respondents say only that children with severe or profound intellectual disabilities "*may be able to access support*" at special schools at an unspecified time in the future. They do not indicate what form this "*support*" will take, they do not say where it will be provided, they do not say to what extent it will be provided, and they do not say when it will be provided.³⁷
67. Further, if and when this happens, they will only be admitted if they are able to "*acquire sufficient skills*",³⁸ or if they "*achieve the minimum outcome and standards linked to the grade of education*".³⁹ Admission to special schools will be on the basis of an assessment of a child's level of educational need. Children who fall inside levels 4 and 5 of the SIAS strategy⁴⁰ will be admitted to special schools. Those whose levels of need are higher than that "*will receive education through partial care centres such as those run by the applicant's members*".⁴¹
68. Thus, even if and when the respondents' policies are implemented, many children with severe or profound intellectual disabilities will still be excluded from schooling provided by the respondents, as they will fall outside levels 4 and 5 of the SIAS strategy.⁴²

(3) 'The subsidy paid compares favourably with expenditure on children not so disabled, and the respondents provide other grants and support'

69. This defence is difficult to understand. The respondents say that the subsidy of R5 092.20 per annum per child, for those children with severe or profound intellectual disabilities who attend special care centres, "*compares favourably*"⁴³ with

³⁶ Tyobeka vol 2 pp 150-151 paras 11.2-11.3.

³⁷ Shaboodien vol 6 p 1979 para 11.3.

³⁸ Tyobeka vol 2 p 158 para 17.

³⁹ Theron vol 3 p 815 para 45.2.

⁴⁰ National Strategy on Screening, Identification, Assessment and Support. See Annexure Tyobeka vol 3 p 702 PT11.

⁴¹ Tyobeka vol 2 p 191 para 70; Theron vol 3 p 815 para 45.2

⁴² Shaboodien vol 6 p 1979 para 11.1.

⁴³ Tyobeka vol 2 p 156 para 13.7; Theron vol 3 p 816 para 49.

- 69.1. the R26 767.00 per child per annum they spend on children with mild to moderate intellectual disabilities who attend special schools;
- 69.2. the R6 632.00 per child per annum they spend on children who attend mainstream schools.
70. It is not clear how it can be contended that an amount which is some 75% less than is spent on each child attending special schools, and some 25% less than is spent on each child attending other schools, can be said to "*compare favourably*". This is unexplained.
71. Even if the subsidy did "*compare favourably*" in absolute terms with the expenditure on other children, this would not constitute a defence, for two reasons:
- 71.1. First, the subsidy is not paid in respect of all of the children who are so disabled: it is paid only in respect of those who are fortunate enough to find a place at a special care centre.
- 71.2. Second, the needs of children with severe or profound intellectual disabilities are greater than those of other children. This is illustrated by the greater expenditure on children in special schools than on those in mainstream schools. The reason for this is the greater needs of children educated in special schools. However, this is not applied to the funding of the education of children with severe or profound intellectual disabilities:⁴⁴ unlike other children, they are not provided with the support which they need.
72. The respondents say that the parents and caregivers of children with severe or profound intellectual disabilities qualify for a care dependency grant of R11 280 per annum, and that this should be seen as a further contribution on their part to the education of such children.⁴⁵
73. The care dependency grant to which the parents and care-givers of these children are entitled, is not a contribution to their education by the respondents. Such care is complex and costly due to the many challenges presented by the disabilities in question. The care dependency grant is a social grant, intended in the main to support the children's care-givers in their care of these children. The grant is not intended as, and is not used as, a means of providing for or supplementing the education of the children.⁴⁶ The state also provides

44 Shaboodien vol 6 pp 1981-1982 paras 11.7 to 11.9.

45 Tyobeka vol 2 p 156 para 13.7; Theron vol 3 p 816 para 49.

46 Shaboodien vol 6 p 1980 para 11.6.

child-support grants and foster care grants, which are not premised on the child's disability. The respondents have never suggested that this absolves them of their obligation to provide those children with a basic education.⁴⁷ Nor could they do so: any such claim would be an egregious breach of the rights to equality and education.

74. The respondents say that they provide additional support to special care centres, such as capacity building of staff and assistance in developing programmes, and providing of facilities.⁴⁸ However, the applicant shows that the respondents' allegations of professional support of the centres by the Western Cape Education Department are exaggerated and misleading. Any support by special schools of special care centres in terms of its "*clustering policy*" is sporadic, and is dependent on existing relationships between schools and centres that pre-date this policy.⁴⁹ In any event, this support does not actually provide education to the children; and the respondents themselves describe these as "*interim measures*"⁵⁰ and do not attempt to portray them as constituting a sustainable policy.

(4) 'The parents of the children concerned must educate them at home'

75. The respondents say that children with severe or profound intellectual disabilities can have certain of their educational requirements provided "*at home by the parents or their caregivers*",⁵¹ and that such children do not necessarily need "*specially qualified teachers and other staff*".⁵²
76. The respondents' attitude requires the parents or caregivers, who are already under severe strain, also to take on the additional burden of the state's responsibility to provide an education to these children.⁵³
77. This attitude is not only callous and heartless: it also disregards the need which Professor Molteno has pointed out, for skilled and experienced staff

⁴⁷ Shaboodien vol 6 p 1980 para 11.6.

⁴⁸ Tyobeka vol 2 p 154 para 13.4; p 180 para 49.5; Theron vol 2 p 805 para 18; p 808 para 27; pp 808-810 paras 28.1-28.6.

⁴⁹ Shaboodien vol 6 p 1980 para 11.5.

⁵⁰ Theron vol 3 p 808 para 28.

⁵¹ Theron vol 3 p 816 para 47.

⁵² Theron vol 3 p 818 para 50.2.3.

⁵³ The applicant refers in this regard to the letters of referral of such children (Shaboodien vol 6 p 2027 FS10), which indicate the severe difficulties presented by the needs of such children, and to a letter from a Dr van der Meulen (Shaboodien vol 6 p 2040 FS14), which indicates that in severe cases, the health of the parent may be placed at risk by the strain.

to address the educational needs of such children.⁵⁴ And it also disregards the constitutional obligations of the state.

78. Professor Molteno, who is an acknowledged expert in the field, describes the contents of the education from which such children can benefit.⁵⁵ As we have pointed out, this approach is internationally accepted. The respondents in fact admit that such children are capable of benefiting from education.⁵⁶ They also admit⁵⁷ Professor Molteno's contention⁵⁸ that such education gives a child a feeling of self-worth and belonging in the world, which in turn promotes human dignity and enables the child to cope with his or her disability to the greatest extent possible. The applicant does not seek to prescribe the content of the "*basic education*" which must be provided to the children concerned. However, Professor Molteno provides a description of the possible content of such an education, based on internationally accepted norms. It includes cognitive development, communication and language development, emotional and social development, physical development and self-care.⁵⁹

(5) 'The respondents cannot provide the children concerned with education, because they have limited resources and competing demands on resources'

79. The respondents say that they have limited resources, they have to make difficult policy choices about the distribution of resources in the face of competing demands, and they are therefore not in a position to make any further contribution to the education of the children in question.⁶⁰ The vast bulk of the respondents' answer to the application is an account of other social and educational services which they provide to people other than the children involved in this case.

80. This defence is fundamentally misconceived. The constitutional rights to basic education and to equality differ from (for example) the rights of access to housing (section 26) or health care services (section 27). Sections 26(2) and 27(2) limit the obligations of the state, by stating that the obligation of the state is to take reasonable measures, within available resources, to achieve the progressive realisation of the right.⁶¹ The rights

⁵⁴ Molteno vol 1 pp97-98 paras 22-23.

⁵⁵ Molteno vol 1 pp93-95 paras 13-16.

⁵⁶ Theron vol 3 p 818 para 51, Cupido vol 5 p 1433 para 44.

⁵⁷ Theron vol 3 p 827 para 84.

⁵⁸ Molteno vol 1 p 95 para 15.

⁵⁹ Molteno vol 1 pp 93-95 paras 13-16.

⁶⁰ Tyobeka vol 2 p 155 para 13.6; Theron vol 3 pp798-805 paras 10-15.

⁶¹ Minister of Health and Others v Treatment Action Campaign and Others (2) 2002 (5) SA 721 (CC) paras [30]-[32].

to equality (section 9) and to basic education (section 29) are not so qualified.

81. It may be that the state could attempt to justify a limitation of the section 9 and 29 rights, in terms of the general limitation clause in section 36 of the Constitution. We deal with this subject separately below. In summary: the respondents have not pleaded a justifiable limitation; they do not identify a law of general application which creates the limitation, which is a necessary element of a justifiable limitation; and they do not allege that such a limitation meets the other requirements of section 36, namely that it is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom.
82. In any event, the additional cost of providing decent basic education to the small number of children is very small in relation to the overall budget. The special care centres in the Western Cape provide education to approximately 1 000 children.⁶² It is estimated that there are approximately 1 500 children with severe or profound intellectual disabilities in the Western Cape.⁶³

A justified limitation of the rights?

83. All rights may of course be limited in accordance with the provisions of section 36 of the Constitution.
84. In this case, a limitation defence does not get to first base. Section 36 provides that a limitation must be in terms of a law of general application. The respondents have not pointed to any law which provides for the denial of basic education to these children.
85. If a limitation claim can somehow pass this obstacle, it fails in any event as a result of the failure to provide any evidence which supports it. In Moise⁶⁴ the Constitutional Court explained the burden of justification in the context of section 36 where a limitation of a constitutional right has been shown:

"[19] It is also no longer doubted that, once a limitation has been found to exist, the burden of justification under s 36(1) rests on the party asserting that the limitation is saved by the application of the provisions of the section. The weighing up exercise is ultimately

62 Shaboodien vol 6 p 1983 para 11.13.

63 Shaboodien vol 1 p 72 FS7.

64 Moise v Greater Germiston Transitional Local Council: Minister of Justice and Constitutional Development intervening 2001 (1) SA 29 (CC)

concerned with the proportional assessment of competing interests but, to the extent that justification rests on factual and/or policy considerations, the party contending for justification must put such material before the Court. It is for this reason that the government functionary responsible for legislation that is being challenged on constitutional grounds must be cited as a party. If the government wishes to defend the particular enactment, it then has the opportunity - indeed an obligation - to do so. The obligation includes not only the submission of legal argument but the placing before Court of the requisite factual material and policy considerations. Therefore, although the burden of justification under s 36 is no ordinary onus, failure by government to submit such data and argument may in appropriate cases tip the scales against it and result in the invalidation of the challenged enactment."

86. In Khosa and Others v Minister of Social Development and Others; Mahlaule and Others v Minister of Social Development and Others,⁶⁵ the Constitutional Court held as follows with regard to a defence based on the cost of giving effect to constitutional rights

"[45] It is also important to realise that even where the State may be able to justify not paying benefits to everyone who is entitled to those benefits under s 27 on the grounds that to do so would be unaffordable, the criteria upon which they choose to limit the payment of those benefits (in this case citizenship) must be consistent with the Bill of Rights as a whole. Thus if the means chosen by the Legislature to give effect to the State's positive obligation under s 27 unreasonably limits other constitutional rights, that too must be taken into account."

87. No evidence has been placed before the court as to the cost of providing basic education to these children; as to why this is unaffordable; and as to the criteria in terms of which it has been decided that the most appropriate way to save this money is to deny these children a basic education.
88. The section 36 enquiry was described by the Constitutional Court in National Coalition for Gay and Lesbian Equality and Another v Minister of Justice and Others⁶⁶ as follows: It

"... involves a process, described in [S v Makwanyane and Another 1995 (3) SA 391 (CC)] as the '... weighing up of competing values,

⁶⁵ 2004 (6) SA 505 (CC)

⁶⁶ 1999 (1) SA 6 (CC)

and ultimately an assessment based on proportionality . . . which calls for the balancing of different interests'.

[34] .. The relevant considerations in the balancing process are now expressly stated in s 36(1) of the 1996 Constitution to include those itemised in paras (a)--(e) thereof... Although s 36(1) does not expressly mention the importance of the right, this is a factor which must of necessity be taken into account in any proportionality evaluation.

[35] The balancing of different interests must still take place. On the one hand there is the right infringed; its nature; its importance in an open and democratic society based on human dignity, equality and freedom; and the nature and extent of the limitation. On the other hand there is the importance of the purpose of the limitation. In the balancing process and in the evaluation of proportionality one is enjoined to consider the relation between the limitation and its purpose as well as the existence of less restrictive means to achieve this purpose.

89. We have described above the nature of the rights concerned. Those rights are crucial in an open and democratic society based on human dignity, equality and freedom. The nature and extent of the limitation is apparent. In many cases, the right of the children concerned to a basic education is nullified, because the state simply makes no provision for their education. Where a subsidy is provided, it is unequal to the provision which is made for children not so disabled, and it is inadequate.
90. We submit that there is no valid justification for the infringement of the constitutional rights of the children concerned to a basic education, equality, dignity, and to be protected from neglect and degradation.

THE RELIEF SOUGHT

91. The applicant accepts that the systemic and sustained breach of the rights of the affected children can not be cured overnight.⁶⁷ What is needed is a reasonable programme which will meet the needs and the rights of the children, and reasonable implementation of that programme.
92. The applicant also accepts that it is not possible or appropriate for the Court to prescribe in detail what the programme must provide.
93. The applicant has been a major driving force in the achievement of the limited progress which has been made. It and its members have a vital interest in ensuring that any order made by this honourable Court is carried out promptly and effectively.⁶⁸
94. We submit that it is in the interests of justice that this honourable Court should order the respondents to submit a programme on what they will do to remedy the breach, and thereafter to report on a periodic basis on what they have done, what more they will do, and when they will do it, and to allow the applicant to comment on the programme so submitted. This would be a form of structural interdict.
95. In this case, there are two reasons why a structural interdict should be granted: first, because the order granted by this court will necessarily be very general and non-specific as to the obligations of the respondents; and second, because the respondents have failed over an extended period to fulfil their obligations, and notwithstanding numerous efforts by the applicant to persuade them to do so.⁶⁹
96. The underlying question is what relief would be appropriate. This is determined by reference to what relief would be effective.
97. In City of Cape Town v Rudolph⁷⁰ this court held as follows:

"Section 38 of the Constitution contemplates that where a right in the Bill of Rights has been infringed, a court may grant 'appropriate' relief. Section 172(1)(b) states that when deciding a constitutional matter, a court may make 'any order that is just and equitable'.

⁶⁷ Shaboodien vol 1 p 28 para 63.

⁶⁸ Shaboodien vol 1 p 28 para 66; pp17-27, paras 23-61.

⁶⁹ Budlender, Geoff & Roach, Kent 'Mandatory relief and supervisory jurisdiction: When is it appropriate, just and equitable?' (2005) 122 2 SALJ 325 at 333-334, and 350.

⁷⁰ 2004 (5) SA 39 (C)

Appropriate or just and equitable relief is relief which will be effective. The relief must be chosen for its ability to protect the constitutional right which is infringed, and fashioned to meet the nature of the infringement. What will be effective, depends on the factual context of the case. If the relief is not effective, the right is not vindicated.

In Fose v Minister of Safety and Security 1997 (3) SA 786 (CC)... Ackermann J said that:

'Appropriate relief will in essence be relief that is required to protect and enforce the Constitution. Depending on the circumstances of each particular case the relief may be a declaration of rights, an interdict, a mandamus or such other relief as may be required to ensure that the rights enshrined in the Constitution are protected and enforced.' ...

'I have no doubt that this Court has a particular duty to ensure that, within the bounds of the Constitution, effective relief be granted for the infringement of any of the rights entrenched in it. In our context an appropriate remedy must mean an effective remedy, for without effective remedies for breach, the values underlying and the right entrenched in the Constitution cannot properly be upheld or enhanced. Particularly in a country where so few have the means to enforce their rights through the courts, it is essential that on those occasions when the legal process does establish that an infringement of an entrenched right has occurred, it be effectively vindicated.'

The circumstances and, in particular, the attitude of denial expressed by applicant in failing to recognise the plight of respondents... makes this an appropriate situation in which an order, which is sometimes referred to as a structural interdict, is 'necessary', 'appropriate' and 'just and equitable'."

98. Our courts have on numerous occasions granted relief in the form of a structural interdict.⁷¹ This form of relief is particularly appropriate where the court does not wish to prescribe to the respondent the detail of what steps must be taken. In those cases, the order is necessarily general in its nature. A structural interdict enables the applicant to monitor what

⁷¹ See, for example, Director of Public Prosecutions, Transvaal v Minister of Justice and Constitutional Development, and others 2009 (4) SA 222 (CC), Nyathi v MEC for Department of Health, Gauteng and another 2008 (5) SA 94 (CC), and the cases cited below.

steps are taken, and if necessary to approach the court for a decision on whether they are adequate.

99. A structural interdict was thus granted in Rail Commuters Action Group and others v Transnet Ltd t/a Metrorail and others (No 1).⁷² The court recognised that “*considerable latitude*” had to be given to the respondents to formulate the means of complying with their constitutional obligations, and that the order made “*should not be at all prescriptive about the solutions which respondents are called upon to implement in order to discharge their obligations*”.⁷³
100. In N and others v Government of Republic of South Africa and others (No 1),⁷⁴ the court recognised that a structural interdict may “*amount to an unwarranted interference with the authority and discretion of the executive arm of government, thereby violating the principle of the separation of powers*”. The court, however, concluded as follows:

“However, nothing rational or workable has been forthcoming from the respondents with regard to the applicants... I am of the view therefore that structured relief is justified based on the facts before me and the circumstances of the case. The respondents submit that this application was unnecessary because they are implementing the operational plan and guidelines. Having carefully considered the evidence before me, I come to the conclusion that such steps as have been shown to have been taken by the respondents are unworkable and characterised by delays, obstacles and restrictions... To my mind, such an order is justified in the special circumstances of this case, more especially, as I see it, there has been and continues to be a violation of the applicants’ constitutional rights. There is nothing forthcoming from the respondents... A structured order with a supervisory component is therefore just, equitable and appropriate”.

101. Similarly, in Kiliko and others v Minister of Home Affairs and others⁷⁵ this court held as follows:

“... as the manner in which the Department discharges its duties and obligations to refugees not only deleteriously affects the freedom and dignity of a substantial number of disadvantaged human beings, but also fails to adhere to the values embodied in

⁷² 2003 (5) SA 518 (C)

⁷³ At 591B

⁷⁴ 2006 (6) SA 543 (D) at para [32]

⁷⁵ 2006 (4) SA 114 (C) at para [32]

the Constitution, I incline to the view that the instant case is an appropriate one for the granting of a structural interdict..."

102. In this case, the applicant has described the lengthy and extensive process of interaction between itself and the respondents over many years.⁷⁶ The applicant has made one effort after another to persuade the respondents to comply with their constitutional duties. Despite this, the respondents have not fulfilled their constitutional obligations. We submit that declaratory relief alone will not ensure that these obligations are met effectively by the respondents, and that a structural interdict is therefore an appropriate remedy in this case.

Costs

103. We submit that, should this application succeed, the respondents should be ordered to pay the costs. This would be in accordance with the usual approach where a civil society group succeeds in obtaining an order requiring the state to comply with its constitutional obligations.
104. The applicant accordingly seeks the relief set out in the notice of motion, and asks that the respondents be ordered to pay the costs of this application, including the costs of two counsel.

**GEOFF BUDLENDER SC
ELSA VAN HUYSSTEEN**

Applicant's counsel
Cape Town
23 April 2010

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⁷⁶ Shaboodien vol 1 pp 17-27 paras 23-61.

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General Comment No 14, 'The right to the highest attainable standard of health', E/C. 12/2000/4

The United Nations Convention on the Rights of the Child

The African Charter on the Rights and Welfare of the Child

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S. Woolman and B. Fleisch, *The Constitution in the Classroom* (2009) Pretoria University Law Press.

IN THE HIGH COURT OF SOUTH AFRICA

(CAPE OF GOOD HOPE PROVINCIAL DIVISION)

CASE NO. 18678/07

In the matter between:

WESTERN CAPE FORUM FOR INTELLECTUAL DISABILITY

Applicant

and

GOVERNMENT OF THE REPUBLIC OF SOUTH AFRICA

First Respondent

GOVERNMENT OF THE PROVINCE OF THE WESTERN CAPE

Second Respondent

NOTICE OF MOTION

KINDLY TAKE NOTICE that the Applicant intends to make application to this Honourable Court for an order in the following terms:-

1. It is declared that the Respondents have failed to take reasonable measures to make provision for the educational needs of severely and profoundly intellectually disabled children in the Western Cape, in breach of the rights of those children to
 - 1.1. a basic education
 - 1.2. protection from neglect or degradation
 - 1.3. equality
 - 1.4. human dignity

2. The Respondents are directed forthwith to take reasonable measures (including interim steps) in order to give effect to the said rights of severely and profoundly intellectually disabled children in the Western Cape, including (but not limited to):
 - 2.1. ensuring that every child in the Western Cape who is severely and profoundly intellectually disabled has affordable access to a basic education of an adequate quality;

 - 2.2. providing adequate funds to organizations which provide education for severely and profoundly intellectually disabled children in the Western Cape at special care centres, such as to enable them to
 - 2.2.1. have the use of adequate facilities for this purpose;

- 2.2.2. hire adequate staff for this purpose;
 - 2.3. providing appropriate transport for the children to and from such special care centres;
 - 2.4. enabling the staff of such special care centres to receive proper accreditation, training and remuneration;
 - 2.5. making provision for the training of persons to provide education for children who are severely and profoundly intellectually disabled.
3. The Respondents are directed, within four months of the date of this order, to deliver to the Applicant and to file at this Court a report, under oath, as to their implementation of paragraph 2 of this order. The said report may deal with any relevant matter that the Respondents wish to raise or report. In addition, the Respondents are required to set out the detail of:
 - 3.1. what steps they have taken to give effect to paragraph 2 of this order;
 - 3.2. what further steps they will take to give effect to paragraph 2 of this order;
 - 3.3. when they will take each such further step to give effect to paragraph 2 of this order
4. The Applicant may, within one month after service upon it of the said report, to deliver its commentary under oath on the said report.
5. The Respondents may, within a further period of two weeks after service upon them of the Applicant's commentary, deliver their reply under oath to the said commentary.
6. The Applicant shall be entitled, if so advised, to enrol the matter for hearing thereafter for a determination of whether there has been compliance with paragraph 2 above and for such other relief as the Applicant may seek in the light of the exchange of information referred to in paragraphs 3,4 and 5 above.
7. The First and Second Respondents will pay the Applicant's costs of this application, the one paying the other to be absolved.
8. Further, other or alternative relief

KINDLY TAKE NOTICE FURTHER that the affidavits of Fatima Shaboodien, Christopher Moltano and Russel Wildeman annexed hereto will be used in support of this application.

The Applicant has appointed the Legal Resources Centre, 3rd Floor, Greenmarket Place, 54 Shortmarket Street, Cape Town, as the address at which it will accept notice and service of all process in these proceedings.

If you intend opposing this application, you must:

- a) by not later than 15 February 2008 notify the Applicant's attorneys in writing and in that notice appoint an address referred to in Rule 6(5)(b) at which you will accept notice and service of all documents in these proceedings, and
- b) within 15 days of notifying the Applicant of your intention to oppose this application, deliver your answering affidavit, if any, together with any relevant documents.

If no such notification is given, the application will be set down for hearing.

DATED AT CAPE TOWN THIS 14th DAY OF DECEMBER 2007

W R KERFOOT

Applicant's Attorney

Legal Resources Centre

IN THE HIGH COURT OF SOUTH AFRICA
(CAPE OF GOOD HOPE PROVINCIAL DIVISION)

CASE NO.

In the matter between:

**WESTERN CAPE FORUM FOR INTELLECTUAL
DISABILITY**

Applicant

and

**GOVERNMENT OF THE REPUBLIC OF
SOUTH AFRICA**

First Respondent

**GOVERNMENT OF THE PROVINCE OF THE
WESTERN CAPE**

Second Respondent

FOUNDING AFFIDAVIT

I the undersigned

FATIMA SHABOODIEN

hereby make oath and say:-

- 1 I am the Chairperson of the Western Cape Forum for Intellectual Disability, and the Principal of the De Heide Special Care Centre in Claremont, Cape Town. I have held the latter position for 22 years. I reside at 246 Buitengracht Street, Cape Town.
- 2 The contents of this affidavit are within my own knowledge unless the context indicates otherwise. Legal submissions contained in this affidavit are made on the advice of my legal representatives.

THE PARTIES

- 3 The **APPLICANT** is the **WESTERN CAPE FORUM FOR INTELLECTUAL DISABILITY FORUM** ("the Forum"), of Asset House, Alexandra Hospital, Annex Road, Maitland. The Forum is a body corporate, and has an

identity and existence distinct from its members and office bearers. It has the right to sue in its own name. I attach (FS1) a copy of the Constitution of the Forum.

- 4 The members of the Forum are non-governmental organizations which care for children in the Western Cape with severe and profound intellectual disabilities. I attach a list of the members of the Forum (FS2). The members of the Forum care for approximately 1 000 children with severe or profound intellectual disabilities.
- 5 At a Forum management meeting held on 21 June 2007, confirming a decision of the Forum AGM held on 16 September 2003, I was duly authorised to bring this application and sign this affidavit on behalf of the Forum. I attach (FS3 and FS4), extracts from the minutes of those meetings containing copies of the Resolution in question.
- 6 **The FIRST RESPONDENT is THE GOVERNMENT OF THE REPUBLIC OF SOUTH AFRICA**, care of the State Attorney, 22 Long Street, Cape Town.
- 7 **The SECOND RESPONDENT is the THE GOVERNMENT OF THE PROVINCE OF THE WESTERN CAPE**, care of the State Attorney, 22 Long Street, Cape Town.
- 8 The Respondents bear the constitutional obligation to respect, protect, promote and fulfil the right of everyone in the Western Cape to a basic education.

THE ISSUE

- 9 The state has established and provides the funding for schools, which include special schools to cater for the needs of children who are classified as having moderate to mild intellectual disabilities (IQ levels of 35-70).
- 10 Children with an IQ under 35 are considered to be severely (20-35) or profoundly (less than 20) intellectually disabled. They are not admitted to the special schools. The state makes no direct schooling provision for them. In the Western Cape, they are almost exclusively catered for by members of the Applicant. The only provision made by the state is that through the Department of Health, it provides a subsidy to organisations which provide this service.
- 11 In the Western Cape, the financial support which the state provides to those organisations is wholly inadequate.

- 12 The result of this situation is that children with an IQ under 35, who are considered to be severely or profoundly intellectually disabled, have not been able to achieve their constitutional rights, and the state fails in its constitutional obligations to fulfil their rights to
- 12.1 the basic education to which they are entitled in terms of section 29(1)(a) of the Constitution;
 - 12.2 the social services to which they are entitled in terms of section 28(1)(c) of the Constitution; and
 - 12.3 the training and skills which they need in order to protect them from maltreatment, neglect, abuse or degradation, to which they are entitled in terms of section 28(12)(d) of the Constitution.
- 13 The state's conduct constitutes a breach of the right to equality in terms of section 9 of the Constitution, as
- 13.1 the amount which the state contributes to the education of these children is unequal in absolute terms, in that it is substantially less than the amount which it contributes to the education of children who have lesser disabilities.
 - 13.2 the state's contribution to the education of these children is substantively unequal, in that the state provides for the needs of children who are not so disabled, with due regard to their actual needs, whereas its provision has no regard to the actual needs of children who are so disabled, and does not provide for their needs, which are in fact greater.
 - 13.3 while the state has established and funded schools for other children, it has not established schools for children who are severely or profoundly intellectually disabled. The only funding which it provides in this regard is in the form of a subsidy to non-governmental organizations which have decided to establish and conduct such schools.
 - 13.4 children who are not so disabled have a right to attend a school which is suitable for them, and the state fulfils that right. The state accepts the obligation to establish enough schools to ensure that every child may enjoy that right. Children who are so disabled are not able to enjoy that right unless they are fortunate enough to find such a Special Care Centre which is conducted by a non-governmental organization and which is willing and able to accept them. The state does not accept the

obligation to ensure that every such child is able to attend an appropriate school.

- 14 The Applicant seeks an order which will require the state to remedy the systemic breach of the rights of the children who are affected.

STANDING

- 15 The aims of the Forum, as set out in its Constitution, are:
- 15.1 To promote the development and continuance of appropriate services for people with intellectual disability.
 - 15.2 To provide support for service providers and consumers.
 - 15.3 To advocate on behalf of people with intellectual disability, their relatives, as well as service providers.
 - 15.4 To provide relevant learning opportunities for service providers.
 - 15.5 To provide an information service.
 - 15.6 To encourage co-operation and liaison between organisations.
- 16 The Forum is particularly concerned with the welfare of children who are severely or profoundly intellectually disabled.
- 17 The Forum brings this application
- 17.1 in its own interest, to promote the achievement of its goals;
 - 17.2 on behalf of the children in the Western Cape with severe or profound intellectual disabilities who cannot act in their own name as a result of their disability and, in the overwhelming majority of cases, their poverty.
 - 17.3 in the interests of its members.

THE FACTS

- 18 The state does not provide any schools in the Western Cape for children with severe or profound intellectual disability.
- 19 In the Western Cape, the only education which is available to children with severe or profound intellectual disability is at Special Care Centres which are run by non-governmental organizations.

- 20 Approximately 1000 of these children are cared for by Special Care Centres, the majority of which are members of the Forum.
- 21 If the children are not able to find a Special Care Centre which is willing and able to admit them they receive no education at all.
- 22 The only provision which the state makes in the Western Cape is that the Department of Health provides a subsidy of R424.35 (ie. approximately R425.00) per month per child to non-governmental organizations which run Special Care Centres.
- 23 As appears from the affidavit of Russell Wildeman (FS5), the average subsidy which the state provides in the Western Cape for schooling in public ordinary schools, for children who are not intellectually disabled, was R6 107.00 in 2006 per year.
- 24 The state provides "LSEN" (Learners with Special Educational Needs) schools for children with moderate to mild intellectual disability IQ of 35-70. As appears from the affidavit of Mr Wildeman, in 2005 the annual subsidy which the state provided for LSEN learners in the Western Cape was R24 549.00 per child.
- 25 Professor Christopher Molteno explains in the attached affidavit (FS6) that children with severe or profound intellectual disability are able to benefit from education and training. He describes in his affidavit the education and training which can be helpful to them.
- 26 Professor Molteno also points out that these children have needs which are very much greater than those of children who do not have this degree of disability. The majority of the children in question have secondary disabilities such as epilepsy, visual and hearing impairment and cerebral palsy.
- 27 It is thus apparent that the state provision for children with severe or profound intellectual disability
- 27.1 is very much less than is provided for other children;
 - 27.2 is inadequate to cater for the educational needs of these children; and
 - 27.3 is only made available where a non-governmental organization provides such facilities.

28 I respectfully submit that this failure to make adequate provision is doubly unlawful:

28.1 It is unlawfully discriminatory, in that the state provision for children with these disabilities is in both absolute terms, and relative to their needs, substantially less than the state provision which it makes for other children. In this regard I respectfully point out that disability is a prohibited ground of discrimination, and that discrimination on that ground is presumed to be unfair.

28.2 It amounts to a failure to fulfil the right of these children to basic education.

ATTEMPTS TO RESOLVE THE PROBLEM

- 23 Since approximately 1997 the Forum has been engaged in negotiations with the Western Cape Department of Education, and to a lesser extent the Western Cape Departments of Health and Social Services, in an attempt to achieve an improvement in the plight of profoundly or severely intellectually disabled children. Every effort has been made to avoid litigation and to resolve the problem by co-operation and negotiation.
- 24 In 1997 financial constraints made it increasingly difficult for the non-governmental organisations which run special care centres to continue to operate. The Forum then spearheaded a lobby to have the Department of Education take responsibility for the education of all children, including the severely or profoundly intellectually disabled.
- 25 After several meetings between October 1997 and mid-1999, the Forum had a meeting with the then MEC for Education in the Western Cape, Ms Helen Zille, and Dr Mathias Theron of the Department of Education Western Cape.
- 26 On 20 September 1999 the Forum provided Dr Theron with written practical suggestions in this regard. Reference was made to Consultative Paper No. 1 on Special Education: Building An Inclusive Education & Training System, First Steps (August 30, 1999. Department of Education with preface by Prof. Kader Asmal, MP, Minister of Education).
- 27 On 28 February 2000 the Forum took MEC Zille and Dr Theron on a tour of four diverse special care centers – in Maitland, Khayelitsha, Makhaya and Claremont respectively. MEC Zille requested that a Task Team be established to address the issue.

- 46 In late June 2002 the Forum submitted to Dr Theron, in response to a request from him, a list of possible areas of support to be offered to the special care centres.
- 47 The issue was to be raised at the National Co-ordinating Committee of Inclusive Education (NCCIE) meeting in October 2002, and recommendations from the meeting were to be made to the Committee of Heads of Education Departments (HEDCOM). I refer in this regard to annexure FS9 hereto, being the minutes of 9 Sept. 2002. Those minutes contain an error stating that NCCIE would make recommendations to NCCIE, instead of HEDCOM.
- 48 On 9 September 2003 the Forum learnt from Dr Theron that the matter had not reached HEADCOM owing to the postponement of meetings, and that the Synergy meeting of the Department of Social Services, Health and Education had not finalised responsibilities for the care, education and support of severed or profoundly intellectually disabled children.
- 49 On 18 March 2004 more than 500 people from 22 special care centres marched to the MEC's office and handed over a memorandum demanding the right to education of special care children.
- 50 On 28 April 2004 a delegation from the Forum had a meeting with the provincial Head of Education (Mr R B Swartz), the Deputy Director-General Education, Planning and Development (Mr Schroeder), the Chief Director Educational Support & Development (Dr Boyse), and Dr Theron (Director Education Support Services).
- 51 Mr Swartz apologised for the long delay in the matter, and referred to the impossibility of double subsidisation. He said that the matter had again been referred to the NCCIE, but the meeting which should have taken place on 3 May had been postponed to June. The matter was also to be referred to HEADCOM.
- 52 On 10 June 2004 the Forum met the new MEC for Education, Mr Cameron Dugmore, and discussed the matter with him. He gave a commitment to complete a consultation process around support for learners with severe or profound intellectual disability, and said that he would convene a meeting between the Forum and the Chief Director to discuss details. Mr Dugmore was supportive of the use of present staff at the special care centres. He suggested that money from the Public Works Department could be used to fund early childhood development workers. He referred to his commitment to the process in his budget speech on 22 June 2004.

- 53 On 26 July 2004 it was agreed at a Joint Top Management meeting of the Departments of Social Services and Poverty Alleviation that the Western Cape Department of Education would provide professional support in the form of training and guiding from all resource schools and Education Management Developmental Centres (EMDC's) to special care centres. This was communicated to the Forum by the Director: Public Health, Mrs K.E. Hillman.
- 54 On 15 February 2005 the Forum had a further meeting with MEC Dugmore. At that meeting, it was agreed that the Western Cape Education Department would submit a proposal to the Committee of Education Ministers. The Forum was to submit a budget proposal to the Western Cape Education Foundation for funding of on-site training at 10 special care centers to the Department. It was also agreed that a particular existing special care centre would be used as a pilot project by being provided with physical space for its premises on the grounds of a LSEN school.
- 55 On 2 March 2005 the Forum received a letter from the Head of Education of the Western Cape Education Department regarding "provisioning of professional support to special day care centres via the Specialised Learner and Educator Support Services (SLES) at the Education Management and Development Centres (EMDCs) and the Special Schools.....discussed and agreed to with the Chief Director: Regional Services (Metropole EMDCs) and the Chief Director: Regional Services (Rural EMDCs).
- The provision of professional support will entail the following:
- Capacity building of staff at the Special Day Care Centres. The SLES components of the relevant EMDC wil liaise with the Special Day Care Centre regarding the training needs of their staff.
 - Special Day Care Centres have been clustered preferably with the nearest special school for learners with severe intellectual disabilities. If this is not possible, the nearest special school should render professional support and therapeutic services..."
- 56 On 26 April 2005 the Forum had a meeting with Dr Sigamoney Naicker, the National Director of Inclusive Education. On 5 May 2005 the Forum provided him with a memorandum on the right to education.
- 57 At the Council of Education Ministers (CEM) meeting of 18 April 2005, the Council agreed to wait for a report back from a task team headed by Dr Naicker, National Director of Inclusive Education, who had been tasked to

investigate the matter on a national level and report back to the CEM on 6 June 2005. As far as I know, this report back never took place.

- 58 The Forum again met Dr Naicker on 31 October 2005, but no progress was made.
- 59 On 24 October 2005 the Forum held a general meeting of its special care centre members with EMDCs and principals of special schools to evaluate the clustering process. The Directorate of Special Needs Education Western Cape was supportive regarding the setting up of this meeting and at the meeting conveyed his support of the process. Concern was expressed about the roll-out by certain EMDCs, with certain EMDCs not even being aware of the process, in spite of having been informed thereof. They had clearly not encouraged their staff and school principals to give support in training, and had not even made contact with the special care centres with which they had been clustered or which fell into their district. The meeting was however well attended by EMDCs, school and special care staff (approximately 81 people).
- 60 Thereafter, despite co-operation from certain special needs schools with Special Care Centres regarding clustering, no further progress has been made with the exception of the pilot project to which I have referred above, where Vukani Special Care Centre has been placed in the grounds of Noluthando School. That Special Care Centre was built and was formally opened in February 2007. It is important to note that other than verbal support from the EMDC, written support from the Deputy Chief Education Specialist: Special Schools, and good co-operation from Noluthando School, the entire process was driven by the Forum and by Newlands Rotary and Peninsula Beverages, which provided the funding and major input.
- 61 Despite all of these efforts, over several years, the inadequacy of the facilities in the Western Cape continues. The fundamental rights of children with severe or profound intellectual disability continue to be breached on a daily basis. The Forum now has no alternative but to ask this honourable Court to compel the Respondents to carry out their constitutional obligations.

RELIEF

- 62 The history of this matter shows that there has been a systemic and sustained breach of the rights of the affected children.

- 63 The Forum accepts that this can not be cured overnight. What is needed is a reasonable programme which will meet the needs and the rights of the children, and then reasonable implementation of that programme.
- 64 The Forum therefore seeks an order in effect requiring the Respondents to take reasonable measures to give effect to the rights in issue.
- 65 The Forum accepts that in the nature of things, it will not be possible or even desirable for this honourable Court to make an order which describes in detail precisely what is to be done, and when it is to be done.
- 66 I submit that it is clear that the Forum has been a major driving force in the achievement of the limited progress which has been made. It and its members have a vital interest in ensuring that any order made by this honourable Court is carried out promptly and effectively.
- 67 I submit that in the light of these factors, it is in the interests of justice that this honourable Court should order the respondents to submit a programme on what they will do to remedy the breach, and thereafter to report on a periodic basis on what they have done, what more they will do, and when they will do it.
- 68 Such reports will create the accountability which I submit is necessary both as a constitutional imperative, and as a means of achieving pragmatic and effective solutions to the problem.
- 69 I submit further that the Forum should be entitled, if it is of the view that the Respondents' programme is insufficient to meet the obligations of the state, or if it is of the view that the Respondents are failing to comply with their obligations, to approach this honourable Court on the same papers (duly supplemented) for appropriate relief. If proceedings have to be initiated afresh, this will lead to a considerable wastage of time and resources.
- 70 The Forum accordingly prays for an order as set out in the notice of motion.

FATIMA SHABOODIEN

I certify that on this day of **DECEMBER 2007**, in my presence at **CAPE TOWN** the deponent signed this declaration and declared that she:

- a) knew and understood the contents hereof;
- b) has no objection to taking this oath;

- c) considered this oath to be binding on her conscience and uttered the words "I swear that the contents of this declaration are true, so help me God".

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A family 'taunted and tormented'

By Anthony Bartram
BBC News, Leicestershire

A single mother who set fire to her car in a Leicestershire lay-by, killing herself and her disabled daughter, had been taunted by gangs for 10 years.

Fiona Pilkington drove 18-year-old Francessca 'Frankie' Hardwick to a lay-by on the A47 and poured petrol on the back seat.

An inquest at Loughborough Town Hall heard 38-year-old Ms Pilkington had repeatedly complained to the police after being targeted by local gangs of youths for 10 years.

Ms Pilkington was a full-time carer for her disabled daughter, who was becoming increasingly difficult to look after as she got older, the inquest heard.

Her son Anthony Hardwick, now 19, is severely dyslexic and had also been targeted by the gang.

Two years after their deaths in October 2007 her family told the inquest that her death was "a final act of desperation" after she could no longer endure the torment.

" She was in despair really, nobody did anything and she was just frustrated "
Grandmother Pam Cassell

They had been constantly taunted by groups of up to 16 youngsters. Stones, eggs and flour were regularly thrown at the family home in Barwell.

Francessca's grandmother Pam Cassell, 72, said her daughter had taped up her letter box the week before she died, fearing that fireworks would be thrown through it.

Mrs Cassell spoke of one ordeal endured by the family.

"It was Halloween and firework night was coming up. Fiona was dreading them because she knew the children would start throwing things at the house and start putting fireworks through the letterbox."

She added: "Frankie was frustrated because she couldn't go out in the garden without being tormented or teased.

"We would take her to the park and take her out in the rain because she used to love jumping in puddles.

"Frankie could be genuinely loveable but when she was frustrated she used to pull hair and bite and punch because she couldn't do what she wanted to do."

Coroner Olivia Davison heard about an incident when Anthony was put into a shed at knifepoint.

But despite dozens of calls to police and Hinkley and Bosworth Borough Council, little was done to help the family.

Mrs Cassell said at one point the council imposed a 300-yard exclusion zone around the house in an attempt to stop the youths, but failed to enforce it.

She said her daughter contacted the council four or five times and phoned police at least ten times a year asking for help.

She said the school holidays and weekends were the worst and her daughter constantly had her curtains closed.

'In despair'

"On the day that they died, Fiona rang up the police and told them children were walking on the hedge and she was told to ignore them.

"The same girls that were walking on the hedge were 'taking the mickey' out of Frankie and imitating the way she walked.

"On another day it was beautifully sunny and I asked why she had the curtains drawn.

"She said the police had told them to do it, so they couldn't see the children walking on the hedge.

"It was going on for so long I thought somebody would have done something. Fiona just gave up."

Mrs Cassell added: "She was in despair really, nobody did anything and she was just frustrated. Nobody was doing anything to help her, not the police, the council or the Neighbourhood Watch."

The inquest heard the family had never taken a holiday together and Mrs Pilkington had never received respite care for her daughter, because she did not know how to apply for it.

Asked by the coroner why Ms Pilkington had taken her daughter out in the car with her that night, Mrs Cassell said : "She didn't think anybody would be able to cope with Frankie. She was getting a lot stronger."

The jury returned a suicide verdict on Ms Pilkington and ruled that her daughter was unlawfully killed.

Story from BBC NEWS:

http://news.bbc.co.uk/go/pr/fr/-/2/hi/uk_news/england/leicestershire/8268521.stm

Published: 2009/09/28 17:42:47 GMT

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Sweatshop allegedly abuses mentally ill

Source: Global Times [08:24 December 14 2010]

Comments



A reportedly enslaved Chinese mentally disabled worker is seen at a building-materials factory near Turpan, in the Xinjiang Uyghur Autonomous Region, Saturday. Photo: IC

By Song Shengxia

A man in southwest Sichuan Province has been arrested for allegedly selling a dozen laborers, most of whom are mentally ill, to a sweatshop in the northwest Xinjiang Uyghur Autonomous Region, a local official said Monday.

Local authorities in the city of Dazhou were still investigating the labor abuse case following Zeng Lingquan's detainment, according to Wang Yong, director the Quxian county Civil Affairs Bureau, who also told the Global Times that the workers were sold to a building-materials factory.

"A work group has left for Xinjiang to bring back the laborers," he said Monday.

A total of 11 workers, including eight mentally disabled people, were found to be working in appalling conditions at the Jiaersi Green Construction Material Chemical Factory in Toksun county, the Xinjiang Metropolitan newspaper reported.

According to the report, the workers have allegedly been confined to the factory, toiling for at least three years without being paid or given any protective uniforms or equipment. And authorities said the workers were forced to live in shabby conditions, not given showers for years and fed the same food as the boss' dogs.

A 40-year-old from Heilongjiang Province, named Wang Li, was among the workers who could communicate relatively well with others. He told the paper that he attempted to escape twice in the past two years, but he was recaptured and badly beaten.

Peng Gengui, another worker, said they were given meat to eat only if they were too weak to work.

Kong Yueyun, 60, who owns a factory that produces marble sandstone close to the Jiaersi factory, speculated on the poor conditions and treatment of the workers. He said he has lived in the town 12 years.

Li Xinlin, owner of the Jiaersi Green factory, told the Xinjiang Metropolitan that his employment of the workers is legal because they were contracted through a disabled persons' aid agency in

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Quxian county called the Quxian Beggars Adoption Agency, which was founded by Zeng Lingquan.

"Zeng set up the agency and sends workers across the country to allow those people who can't take care of themselves ... to make a living on their own," Li told the paper.

According to a contract, shown by Li to the local paper, for five workers transferred as the second batch to the factory, the factory is required to pay the agency a lump-sum of 9,000 yuan (\$1,323), plus 300 yuan per month per worker, and to compensate the agency 1,000 yuan for each worker lost. The workers did not receive any pay.

In similar factories, the average daily salary for a worker is at least 150 yuan, and laborers do not need to work between November to March due to cold weather, Kong said.

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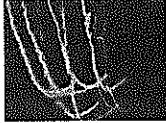
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Sweatshop allegedly abuses mentally ill

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Comments

Local police said they could do nothing regarding conditions or pay because the factory has a labor contract with the Sichuan Civil Affairs Department.

According to Wang Yong at the county's Civil Affairs Bureau, there was no organization in the county registered as the Quxian Beggars Adoption Agency, adding that there was only one official relief station in the county aiming to help all types of vulnerable groups, including physically and mentally disabled people.

Zeng was previously been found to have engaged in human trafficking. In 2007, he was wanted by police in Leiyang, Hunan Province, in connection with a case in which he was found to have sold beggars to a brick factory in Leiyang where a beggar was tortured to death, the Legal Weekly reported.

Zeng, who remains at large, was said to have been previously praised by the local government in Sichuan for "his success in solving the issue of beggars," according to the report.

Cases involving mentally disabled people being sold and used as forced laborers have been reported throughout the country.

In 2006, police in Zhengzhou, Henan Province, arrested Zhou Jinghuan, a local woman, who was found to be selling around 1,000 people a year to brick factories or mines in the province for 170 yuan each, to be used as forced labor, CCTV reported. Most of the people she sold were beggars or mentally disabled.

Dong Baohua, a Shanghai-based lawyer, told the Global Times that there were laws on the employment of the disabled people to safeguard their labor rights, the laws set up only "overall" principles.

"The existence of a labor agreement is by no means a sound reason for the police to stop further investigation, because the labor agreement does not give the factory the right to mistreat the workers," Dong said.

Dong also suggested that the Disabled Persons Federation enhance its relations with legal aid organizations to better help the disabled who are vulnerable to labor traffickers.

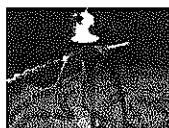
Huang Jingjing and Cao Xiaochen contributed to this story

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Disabled girl starved, left to die

August 2, 2008 12:15 am

BY KATHY MATHESON

BY KATHY MATHESON

ASSOCIATED PRESS WRITER

PHILADELPHIA

--For days before Danieal Kelly died in a fetid, airless room--made stifling hot by a midsummer heat wave--the bedridden teenager begged for something to drink until she could muster only one word: water.

Unable to help herself because of her cerebral palsy, she wasted away from malnutrition and maggot-infested bedsores that ate her flesh. She died alone on a putrid mattress in her mother's home, the floor covered in feces. She was 14 but weighed just 42 pounds.

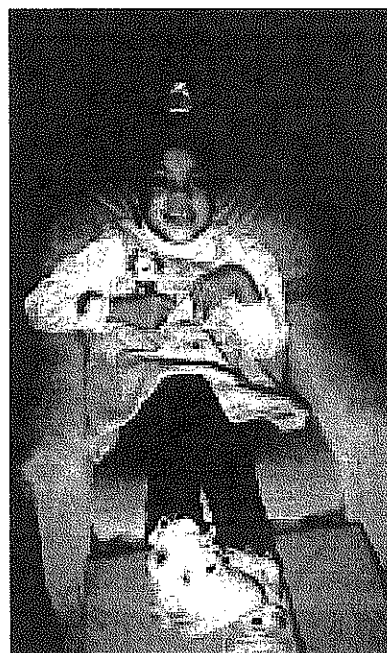
The nightmare of forced starvation and infection that killed Danieal while she was under the protection of the city's human services agency is documented in a 258-page grand jury report released this week that charges nine people--her parents, four social workers and three family friends--in her ghastly death.

The report describes a mother, Andrea Kelly, who was embarrassed by her disabled daughter and didn't want to touch her, take her out in public, change her diapers or make sure she had enough fluids. It portrays Daniel Kelly, the father who once had custody of Danieal, as having no interest in raising her.

And it accuses the city Department of Human Services of being "uncaring and incompetent."

"It was this indifference that helped kill Danieal Kelly," an angry District Attorney Lynne Abraham said. "How is it possible for this to have happened?"

The report should "outrage the entire Philadelphia community" and bring about "earth-shattering, cataclysmic changes" at the Department of Human Services, Abraham said.



Danieal Kelly is seen in this undated photo released by the Philadelphia District Attorney's Office.



Contract social worker Mickal

Andrea Kelly, 39, the only defendant charged with murder, was ordered held yesterday without bail. The social workers--suspected of falsifying home visits and progress reports in the case--face charges ranging from child endangerment to involuntary manslaughter. The family friends are accused of lying to the grand jury about the girl's condition before her death.

Kamuvaka is escorted by a Philadelphia police detective Thursday.

None of the lawyers for any of the defendants had any immediate comment.

Human Services Commissioner Anne Marie Ambrose, in office only a month, said Thursday that she is intent on improving child safety and worker accountability in an agency that has repeatedly been accused of failing to protect children.

The report on Danieal's death in August 2006 documents a downward spiral from the early years that she spent in Arizona with her father and his girlfriend.

Though Danieal attended special-needs classes only sporadically, a school report described her as an active learner and "one of the sweetest students ever enrolled in this program." But allegations of parental neglect soon surfaced, and following Daniel Kelly's breakup with his girlfriend in 2001, Danieal never again attended school.

Daniel Kelly and his children moved to Philadelphia in 2003. He eventually asked his estranged wife to move in, even though she had several other children and he knew she was incapable of caring for Danieal, authorities say. He then moved out.

The Department of Human Services received at least five reports of Danieal's being mistreated between 2003 and 2005. All described a "helpless child sitting unattended, unkempt and unwashed, in a small stroller in her own urine and feces," her screams ignored by her mother, the grand jury report said.

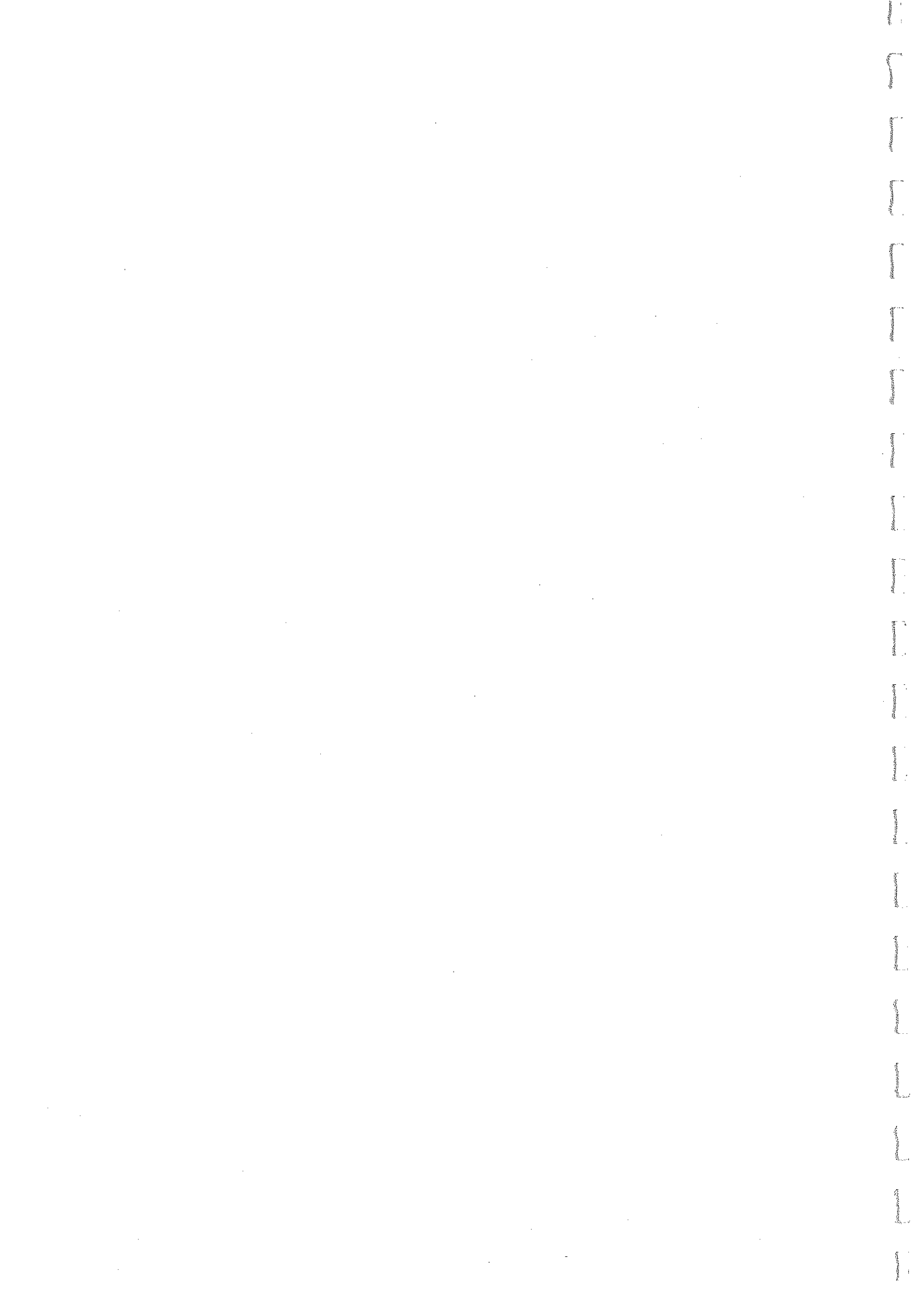
Agency employee Dana Poindexter, assigned to investigate, also ignored Danieal, authorities say. Already having been suspended after a 3-week-old baby died on his watch in 2002, Poindexter continued his "slovenly, neglectful and dangerously reckless work habits" after being assigned the Kelly case, the grand jury said. He did not file a single report, authorities said.

The Kellys finally were assigned help from a private agency in 2005. Employee Julius Murray was required to visit the family twice a week, but authorities believe he may have come to the house only once--to have Andrea Kelly sign predated forms attesting to future visits.

The grand jury report said Laura Sommerer, a city social worker, failed to hold the now-defunct company accountable when, months later, Danieal still was not enrolled in school or receiving medical care.

And after Danieal died, authorities say, company director Mickal Kamuvaka held a "forgery fest" in her office where she had employees "concoct almost a year's worth of false progress reports."

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SOUTHERN AFRICA LITIGATION CENTRE

SECTION 9

EXTRA READING

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Extra Reading:

- 1. Concepts and Principles of the CRPD**
- 2. Sexual and Reproductive Health Rights of PWD**
- 3. Education Rights for PWD**

Please Note: These notes are a Working Draft of a manual that is being developed by SALC. They are not for public dissemination and merely attached to add value to the course pack and to give a deeper understanding to participants' of some of the issues under each thematic topic.

Concepts and Principles of the Convention on the Rights of Persons with Disabilities

1 Defining “disability”

The Convention’s authors were unable to come to an agreement about the definition of “disability,” due at least in part to philosophical differences about whether to adopt the medical or social model of disability. The International Disability Caucus,¹ which advocated successfully for the social model of disability, argued that defining “disability” in fixed terms would be using the disfavoured medical approach.²

There is no definition of “disability” under article 2, but other parts of the Convention do give some meaning to the term. For example, the Preamble clearly espouses the social model of disability:

(e) *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

Additionally, the second paragraph of article 1 gives guidance as to who is covered by the Convention, though it avoids defining “disability” itself. Persons with disabilities *include* those with “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” This is not an exhaustive list, but it at least implies that long-term impairments of the type described qualify as disabilities.

2 Core principles of the CRPD

The Convention on the Rights of Persons with Disabilities is anchored in eight general principles, articulated in article 3. The principles are:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- b. Non-discrimination;
- c. Full and effective participation and inclusion in society;
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. Equality of opportunity;
- f. Accessibility;

¹ The IDC is a network of global, regional and national organisations of person with disabilities and allied NGOs and was a key player in the negotiation of the CRPD. See International Disability Association, *About Us*, <http://www.internationaldisabilityalliance.org/en/about-us>.

² International Disability Caucus News Page, Feb. 1, 2006, <http://www.ideanet.org/content.cfm?ID=58547F>.

- g. Equality between men and women;
- h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

This article of the Convention recognises a core set of concepts that, though not unique to the CRPD, are of particular importance in the disability context. By articulating the general principles early in the text, the authors of the CRPD made sure that all the rights expressed in the rest of the document are interpreted through the lens of article 3.³

While all eight of the principles are important and relevant throughout the Convention, this chapter focuses on three in particular: non-discrimination, equality of opportunity and accessibility. These three principles require the most clarification of the list in article 3, and they are also the concepts that are touched upon in every right conferred in the rest of the Convention. For these reasons, the rest of the chapter is dedicated to clarifying the meaning of these three central principles.

3 Equality

In a human rights context, “equality” means that all humans possess the same dignity and are inherently entitled to the same rights, regardless of our differences from one another.⁴ The principle of equality requires every individual and every society to accommodate human differences, including differences based on disability.⁵

There are many different ways of thinking about and applying the principle of equality. One option is to simply pass laws that formally prohibit discrimination or require all groups of people to be treated the same – this is known as “**formal equality**.” Another approach is often referred to as “**equality of opportunity**” and requires moving beyond formal announcements of equality in law and making sure persons with disabilities can enjoy the same opportunities as everyone else. A third approach, “**substantive equality**,” tries to guarantee equal outcomes (not just opportunities). Each of these approaches to equality is discussed in more detail below.

Formal equality

³ Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities, pg. 11 (2007).

⁴ See Universal Declaration of Human Rights, art. 1, <http://www.un.org/en/documents/udhr/>.

⁵ Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities, pg. 25 (2007).

Formal equality can be traced back to Aristotle and his pronouncement over 2,000 years ago that “things that are alike should be treated alike.”⁶ This model of equality assumes that real equality will be achieved if the law treats all persons exactly the same. However, in the context of historic discrimination and entrenched prejudice, the formal equality model cannot address real inequality in circumstances between differently-situated individuals (for example, a person with a disability and a person without a disability in the context of an inaccessible society).

In fact, formal equality has long been criticised and is disfavoured in human rights law today. Detractors have characterised formal equality as “empty of content,”⁷ but the central criticism is that, “by treating different individuals as equals *despite their unequal access to power and resources*,”⁸ it created an illusion of equality while allowing real economic, legal, political and social disparities to grow.

This discussion is not meant to suggest that formal equality is unimportant. Laws requiring all groups to be treated equally and prohibiting discrimination are a necessary starting point for achieving true equality for disadvantaged and marginalized groups. Moreover, in the field of disability, laws that discriminate in an outright manner on the basis of disability are still embedded in many systems, such as laws denying voting rights or authorizing disability-based detention, and many more. However, it is not enough by itself to achieve equality of opportunity. Additional steps need to be taken.

Equality of opportunity

Equality of opportunity recognises that people may face limitations in their lives resulting from circumstances completely out of their control (like their race, gender or disability). These circumstances can make it very difficult or even impossible for persons with disabilities and other historically marginalized groups to participate in society on an equal footing with others; equality of opportunity therefore departs from the traditional notions of formal equality and suggests that certain extra measures must be taken to correct past discrimination and injustice, because a failure to do so would leave individuals and groups in different starting points.⁹

⁶ Aristotle, *Ethica Nicomachea*, vol. 3.

⁷ Peter Westen, *The Empty Idea of Equality*, 95 HARV. L. REV. 537, 537 (1982).

⁸ *Factum of the Intervenor, Law Society of British Columbia & Anor. v Andrews & Anor.*, [1989] 1 SCR 143, available at <http://www.ccdonline.ca/en/humanrights/promoting/andrews>, at Part III, para 3 (emphasis added).

⁹ <http://www.equalrightstrust.org/ertdocumentbank/The%20Ideas%20of%20Equality%20and%20Non-discrimination,%20Formal%20and%20Substantive%20Equality.pdf>, pg. 3

This approach to equality is *only* concerned with opportunities – once a fair playing field is established, the “winners” will be determined by factors like talent, hard work, etc. In other words, after members of traditionally disadvantaged groups are given the allowances necessary to put them on an equal footing with other groups, the results are largely irrelevant.

In the disability context, equality of opportunity requires specific actions to be taken to ensure that persons with disabilities can enjoy the same opportunities as other people. This includes ensuring accessibility of transportation, combating stereotypes that lead to discrimination and providing reasonable accommodation to allow students and employees the chance to thrive. More broadly it requires removing built-in barriers, whether environmental or attitudinal, that put persons with disabilities at a disadvantaged starting point.

Substantive equality

Substantive equality (also sometimes called “equality of outcomes”) seeks to ensure the equality of results, not just the equality of opportunities. Often the only way to guarantee this type of equality is to implement so-called “positive discrimination,” whereby persons are explicitly treated more favourably on the grounds of race, sex, disability, etc. This could take the form of, for example, an employer preferring to hire or promoting a person with disabilities from a pool of qualified candidates because of the person’s disability. ¹⁰ This approach to equality is very politically controversial.

4 Non-discrimination

To understand what *non-discrimination* entails, it is necessary to first understand what discrimination means. In one sense, to “discriminate” simply means to *distinguish* one thing from something else, and it is neither an inherently good nor bad action. ¹¹ However, it can also take on a much more negative meaning when it is used to describe treatment of people based on something other than individual merit: ¹² this is usually described as someone being “discriminated *against*.”

To say that a person has been discriminated against typically means that they have been treated not only differently on the basis of some particular characteristic, but also unfairly. The CRPD defines “discrimination on the basis of disability” as

¹⁰ <http://www.equalrightstrust.org/ertdocumentbank/The%20Ideas%20of%20Equality%20and%20Non-discrimination,%20Formal%20and%20Substantive%20Equality.pdf>, pg. 4

¹¹ Merriam-Webster.com, “discriminate,” <http://www.merriam-webster.com/dictionary/discriminate>.

¹² Merriam-Webster.com, “discriminate,” <http://www.merriam-webster.com/dictionary/discriminate>.

“any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.”¹³

International law formally distinguishes between “direct” and “indirect” discrimination (sometimes also called “purpose” and “effect” discrimination, as in the CRPD).¹⁴ Direct discrimination is treatment that is blatant and intentionally disadvantageous to persons with disabilities, like a law specifically banning children with disabilities from attending public schools. Indirect discrimination occurs when a policy or situation is neutral, but has a disproportionately negative impact on persons with disabilities because it does not take their needs into account. This is the case where, for example, municipal or government buildings are accessible only by stairs, effectively excluding people in wheelchairs from accessing government officials.

The CRPD’s definition encompasses both direct and indirect discrimination, and article 5(2) prohibits all discrimination on the basis of disability. The Convention’s principle of “non-discrimination” therefore encompasses a commitment not to engage in discriminatory conduct and to take steps to counter both obvious and more subtle forms of discrimination. States must actively address discrimination between private individuals in addition to discriminatory legislation and policies.¹⁵

Non-discrimination does not mean identical treatment in every situation.¹⁶ This is because of the way the principles of non-discrimination and equality¹⁷ operate together: historic discrimination against persons with disabilities that has led to unequal conditions and opportunities requires a range of steps to remedy it, including neutralizing and removing barriers that disadvantaged persons with disabilities to begin with, and providing

¹³ CRPD, art. 2.

¹⁴ See Comm. on Economic, Social and Cultural Rights, General Comment No. 20 (2009): Non-Discrimination in Economic, Social and Cultural Rights, para. 10, at <http://www2.ohchr.org/english/bodies/cescr/comments.htm> (“Both direct and indirect forms of differential treatment can amount to discrimination under [the ICESCR]”); Human Rights Comm., *Derksen v Netherlands*, Comm. No. 976/2001, para. 9.3, U.N. Doc. CCPR/C/80/D/976/2001 (2004) (“The Committee recalls that Article 26 prohibits both direct and indirect discrimination, the latter notion being related to a rule or measure that may be neutral on its face without any intent to discriminate but which nevertheless results in discrimination because of its exclusive or disproportionate adverse effect on a certain category of persons.”).

¹⁵ Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities, pg. 27 (2007)

¹⁶ Human Rights Comm., General Comment No. 18 (1989): Non-Discrimination, para 8, at <http://www2.ohchr.org/english/bodies/hrc/comments.htm>.

¹⁷ See section 2.3, *supra*.

accommodations to level the playing-field. These derive from the notion of equality and non-discrimination. Finally, taking special and specific measures that go beyond removal of barriers and accommodation may be necessary to facilitate equality. “Specific measures” are recognized in international law, and also sometimes referred to as “affirmative action.” Article 5(4) of the CRPD recognises that “[s]pecific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.”

The objective of specific measures is to achieve equality by treating persons with disabilities in a way that accords them some advantage over persons without disabilities. For example, policies aimed at encouraging employers to hire and promote persons with disabilities are likely to favour persons with disabilities over other workers. Although these actions do result in different treatment on the basis of disability, they are not considered “discrimination” under the CRPD¹⁸ because their goal is to overcome previous inequality. In fact, by the terms of the CRPD, *refusal* to provide for reasonable accommodation (which is inherently differential treatment) is considered a form of disability-based discrimination.¹⁹

While the economic, social and cultural rights in the Convention are subject to progressive realisation,²⁰ the Committee on the Rights of Persons with Disabilities has stressed that duty to prohibit non-discrimination and to provide reasonable accommodation is “immediately applicable and not subject to progressive realization.”²¹

5 Accessibility

Any discussion of the human rights of persons with disabilities must include some consideration of accessibility. After all, no one can exercise a human right which they cannot access, and there are many obstacles that impede person with disabilities’ full enjoyment of their rights. Under the social model of disability espoused in the CRPD, we can easily recognize that in most cases these “obstacles” are a reflection of societal structures (both physical and non-physical) which to begin with did not take into account people with disabilities. These barriers then are part of the concept of “disability” in the sense of outside factors creating the disability. The Preamble of the CRPD notes:

¹⁸ Different countries’ municipal laws define “discrimination” in various ways, and affirmative action may or may not be legal under domestic laws.

¹⁹ CRPD, art. 2.

²⁰ CRPD, art. 4(2).

²¹ Concluding Observations of the Comm. on the Rights of Persons with Disabilities (Spain), para 44, U.N. Doc. CRPD/C/ESP/CO/1 (Oct. 19, 2011), at <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session6.aspx>.

(e) *Recognizing* that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.

The preamble recognises both attitudinal and environmental barriers that can impair accessibility. There are also informational and institutional barriers that can additionally impact person with disabilities' ability to access their human rights.²²

- **Physical**: These barriers include environmental barriers, especially those that exist in the built or manmade world. They are typically the first barriers that people think of when considering access for people with disabilities, as they are the most obvious. For example, many people are aware of the value of ramps for wheelchair access to buildings. However, other physical barriers may be less readily apparent. For instance, people may not be aware of the need for tactile surfaces to assist people with visual impairments as they navigate the built environment around them.

- **Informational**: Both the form and content of information can constitute barriers to access for people with disabilities. The form of information may constitute a barrier to access if, for example, published literature or websites use small print that are difficult to read for people with low vision. Television shows and advertising that do not include captioning, subtitles or a setting for sign language will be inaccessible to people who are deaf. Written information that is not also provided in Braille or other appropriate tactile forms may be inaccessible to people who are blind. The content of information is also of critical importance. For example, information that is not provided in plain language is likely to be inaccessible to many people with intellectual disabilities.

- **Institutional**: These barriers include legislation and/or practices that actively prohibit or fail to facilitate access by people with disabilities. For example, in some countries people with psychosocial disabilities are expressly barred from voting based on their disability. Other people with disabilities may be unable to vote not because of an express prohibition, but because of practices that do not ensure everyone can gain physical access to polling venues or voting booths. There may additionally be problematic legislation or practices that do not guarantee access to the ballot and other voting information.

²² The following discussion of the types of barriers is adapted from Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities, pg. 37-38 (2007).

- **Attitudinal:** Perhaps the most pervasive barrier is people's attitudes about the meaning and limitations of disabilities. Sometimes barriers to accessibility are created or maintained simply because members of society are generally unaware of their existence and the detrimental effect they have on the lives of people with disabilities. Such lack of awareness can have especially detrimental consequences in the area of technology. Although technology has the potential to enhance access for people with disabilities, technological advances that fail to consider the need for accessibility features can create barriers to one of today's major avenues of community and social development. At a time when people increasingly rely on mobile phones and the internet as sources of information and means of communication, many of the devices and software programmes are not usable by people who are deaf, blind or deafblind, leading to further marginalization and exclusion of these groups.

5.1 Universal Design

The concept of *universal design* seeks to create products, environments, programmes and services that are *inherently accessible* to all people, both with and without disabilities. As explained in article 2 of the CRPD, the use of universal design aims to ensure access "by all people, to the greatest extent possible, without the need for adaptation or specialized design." When a product is made according to a universally usable design, each one is exactly the same and equally navigable by a broad swath of the population; there is theoretically no need to make adjustments for people with disabilities in order to facilitate access.

Universal design is especially important in situations where it is difficult or impossible to tailor an experience to each individual user's accessibility needs. For example, when constructing a new park or sports arena, following universal design principles can ensure access by as many potential users as possible; taking individual needs into account in these types of settings would otherwise be very difficult.

The seven principles of universal design are:²³

- **Equitable use:** the design is useful and marketable to people with diverse abilities;
- **Flexibility in use:** the design accommodates a wide range of individual preferences and abilities;

²³ North Carolina State University, Center for Universal Design, *The Principles of Universal Design*, version 2.0, Apr. 1, 1997, <http://www.ncsu.edu/project/design-projects/udi/center-for-universal-design/the-principles-of-universal-design/>.

- **Simple and intuitive use:** use of the design is easy to understand, regardless of the user's experience, knowledge, language skills or current concentration level;
- **Perceptible information:** the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities;
- **Tolerance for error:** the design minimizes hazards and the adverse consequences of accidental or unintended actions;
- **Low physical effort:** the design can be used efficiently and comfortably and with a minimum of fatigue; and
- **Size and space for approach and use:** appropriate size and space is provided for approach, reach, manipulation and use, regardless of the user's body size, posture or mobility.

5.2 Reasonable Accommodation

While universal design treats all users the same and focuses on the overall usability of the product, service or environment, it may not be successful in providing access for every individual in every situation. When universal design is insufficient, *reasonable accommodation* can help to further increase accessibility for people with disabilities. As defined in the CRPD, "reasonable accommodation" is a process through which "necessary and appropriate modification and adjustments" are made in order to accommodate the accessibility needs of a particular person.²⁴ In other words, it is a specific response to the unique accessibility needs of an individual. However, as implied by the term, the accommodation must be *reasonable*, and it is not required where providing it would impose a "disproportionate or undue burden"²⁵ on whoever is making the accommodations. What is considered reasonable will vary depending upon the size and resources of the person or organisation providing the accommodation. The reasonableness of a particular type of accommodation will also vary over time, as new ways to overcome accessibility barriers become available.

Because of the individualised nature of accommodations, reasonable accommodation is a process that is well-suited to educational and employment settings, where long-term accessibility solutions facilitate the enjoyment of the rights to education or work. For example, in a classroom setting, a student with a learning disability might be accommodated

²⁴ CRPD, art. 2. As commented above, accommodations must be tied in to equality and non-discrimination. See CRPD Article 5(3). That is also how it appears in national laws, as one manifestation of equality, or even more explicitly: not providing reasonable accommodations is one manifestation of discrimination.

²⁵ *Id.*

through the provision of a note-taker or extra time to complete exams. In an office environment, reasonable accommodation could include ensuring that the workspace is navigable for a wheelchair user, providing other assistive technologies to facilitate computer use by someone with a visual impairment, or enabling flexibility in work hours to needs arising from the disability in the context of the demands of the workplace.

Ultimately, accessibility is fundamental for persons with disabilities to ensure their inclusion and participation as full and equal members of society. Lack of access can prevent people with disabilities from wholly enjoying any human right. For example, the lack of accessible transportation not only prevents enjoyment of the right to liberty of movement, but it can also prevent people with disabilities from travelling to places of work, education, health care, rehabilitation, culture, sports and other venues where different human rights are enjoyed. As always, the human rights of persons with disabilities are indivisible, interdependent, and interconnected. As a result, discussion of how any human right can be fully enjoyed by people with disabilities must include consideration of access.

Sexual and reproductive health

There are approximately 300 million women with disabilities around the world.¹ These women experience compounded stigma on the basis of their gender and their disability, exacerbating difficulties others encounter when trying to exercise their rights related to sexual and reproductive health (SRH).

While both men and women with disabilities experience rights violations related to their sexual and reproductive health, this chapter focuses on women because of the disproportionate impact denial of sexual and reproductive health information and services can have on their lives. SRH issues specific to women with disabilities include forced or coerced sterilisations and abortions, pre- and post-natal and maternal information and care and the so-called “Ashley treatment.”² The high incidence of sexual violence against women with disabilities also puts them at increased risk for HIV infection.³

The SRH needs of persons with disabilities are frequently overlooked, often because of faulty assumptions that persons with disabilities are or ought to be sexually inactive. But persons with disabilities have the same needs for sexual and reproductive health services as the rest of the population. In fact, persons with disabilities may actually have greater needs for SRH education and care than persons without disabilities due to their increased vulnerability to sexual abuse. The drafters of the key human rights conventions recognised these realities, and the SRH rights of persons with disabilities are protected under international human rights law.

The 1993 Vienna Declaration and Programme of Action asserts that ‘[s]pecial attention’ must be paid to ensuring ‘non-discrimination, and the equal enjoyment of all human rights and fundamental freedoms by disabled persons.’⁴ More recently, the preamble of the Convention on the Rights of Persons with Disabilities recognises the need to ‘promote and protect the human rights of all persons with disabilities,’⁵ and the importance of PWDs’ ‘individual autonomy and independence.’⁶ Reproductive rights are among these fundamental freedoms and rights, including the right to found a family; the right to comprehensive health care, including sexual and reproductive health, family planning and maternal health services; and the right to be protected from torture and medical treatment without informed consent, including sterilisation and abortion.

This list is not exhaustive. Other rights may be implicated when a woman has difficulty accessing SRH services, including *inter alia* the rights to non-discrimination, to life, to privacy, to physical integrity and/or to dignity.

¹ USAID, *Women with Disabilities*, http://transition.usaid.gov/our_work/cross-cutting_programs/wid/disability/wwd_statistics.html.

² This term refers to the process of removing a disabled child’s sex organs, breast buds, and stunting growth with hormone treatments. It is commonly called the ‘Ashley Treatment’ after the first known child to undergo the procedure. Though there are reports of young boys with disabilities being treated with stunting hormones, it appears the removal of sex hormones has so far only been performed on girls with disabilities. See National Disability Rights Network, *DEVALUING PEOPLE WITH DISABILITIES: MEDICAL PROCEDURES THAT VIOLATE CIVIL RIGHTS* 5 (2012).

³ UNAIDS, WHO & OHCHR Policy Brief: Disability and HIV, pg. 2-3 (2009).

⁴ Vienna Declaration and Programme of Action, World Conference on Human Rights, Vienna, Austria, 14-25 June 1993, at Art. 22, U.N. Doc. A/CONF.157/23 (1993)

⁵ CRPD, preamble (j).

⁶ CRPD, preamble (n).

Right to found a family

The CRPD guarantees respect for home and the family under article 23:

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
 - a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;
 - b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;
 - c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

The Committee on the Rights of Persons with Disabilities has not yet interpreted this article of the Convention, but its terms are clear. Under article 23(1)(b), PWDs are guaranteed equal access to reproductive health education and ‘the means necessary’: in practice, this almost surely is access to sexual and reproductive health services, discussed at length *infra*. Article 23(1)(c) clearly bans discriminatory forced sterilization⁷ programmes targeting persons with disabilities.

The ICESCR also guarantees protection to the family unit in its article 10. Specifically, article 10(2) states:

2. Special protection should be accorded to mothers during a reasonable period before and after childbirth. During such period working mothers should be accorded paid leave or leave with adequate social security benefits.

The Committee on Economic, Social and Cultural Rights (CESCR) stated in its General Comment No. 5 that women with disabilities are entitled to the right to protection and support outlined in article 10(2) in relation to motherhood and pregnancy.⁸ Recognising the needs and desires of women with disabilities to have sexual relationships in both the ‘recreational and the procreational contexts,’ the Committee stated that ‘[b]oth the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10(2).’⁹

CESCR’s General Comment No. 5 also makes reference to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.¹⁰ Though the Rules themselves are not legally binding, they are an ‘authoritative guide’ for Member States¹¹ Additionally, human rights committees regularly refer to the Standard Rules when discussing persons with disabilities and their rights under the various conventions. The committees have the authority to interpret the provisions of their respective conventions and to clarify content; by referring

⁷ Compulsory or forced sterilization is a medical procedure that results in the permanent and irreversible removal of an individual’s ability to reproduce without his or her consent.

⁸ Comm. on Econ., Soc. & Cultural Rights, General Comment No. 5: Persons with disabilities (1994), para. 31.

⁹ *Id.*

¹⁰ *Id.*

¹¹ Statement by the Special Rapporteur on Disability to the 42d Sess. of the Commission for Social Development, Feb. 2004, <http://www.un.org/disabilities/default.asp?id=57>.

to the Rules, they suggest that the Rules should similarly be applied to meaningfully clarify the scope and substance of the legally binding convention articles.

Standard Rule 9 relates to family life and personal integrity. The rule urges States to promote the full participation of persons with disabilities in family life, including with respect to sexual relationships, marriage and parenthood. Rule 9(2) goes on:

“Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counselling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.”

This obligates States to not only disallow discrimination against persons with disabilities, but also to take affirmative action to facilitate their ability to participate in normalised sexual and domestic relationships. States must also provide equal access to sexual and reproductive health services and accessible information. Though the Rules predate the CRPD, it would be most consistent with the spirit of the Convention to provide the information in the manner as defined by ‘communication’ under article 2 of the CRPD: ‘languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.’

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) provides for non-discrimination against women in all matters related to marriage and family relations in article 16. States must ensure, on a basis of equality of men and women, *inter alia*, ‘the same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.’¹² The CEDAW Committee’s General Recommendation No. 18 was adopted in 1991 to ensure that States Parties understood the Convention, including article 16, extends to women with disabilities.¹³

Right to health

Like the right to found a family, the right to the enjoyment of the highest attainable standard of health is well-recognised, and it is articulated in a number of international human rights treaties.

Article 25 of the CRPD recognises that PWDs have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, and States must take ‘all appropriate measures’ to ensure access to gender-sensitive health services. Specifically, States Parties shall, *inter alia*,

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, *inter alia*, raising awareness of the

¹² CEDAW, *supra* note X, at art. 16(1)(e).

¹³ CEDAW Committee, General Recommendation No. 18: Disabled Women (1991).

human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

As a reminder, the CRPD defines 'discrimination on the basis of disability' as

'any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.'¹⁴

Again, since the Committee on the Rights of Persons with Disabilities is so new, it has not offered guidance on how to interpret the Convention's right to health. However, it seems likely that the procedures involved in the so-called 'Ashley Treatment,' whereby a young girl with disabilities is operated on *because of her disabled status* to have her reproductive organs and breast buds removed and undergoes growth attenuation, would violate CRPD article 25.

The ICESCR's right to health announced in article 12 is much more thoroughly developed, both in general terms and as it relates to sexual and reproductive health. Article 12 states, in relevant part:

1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
 - (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
 - ...
 - (c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
 - (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

As the CESCR made clear in its General Comment No. 14, the ICESCR prohibits discrimination in the implementation of article 12 on the basis of disability:

'By virtue of article 2.2 and article 3, the Covenant proscribes any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, *physical or mental disability*, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.'¹⁵

Additionally, paragraph 34 of General Comment No. 5 (which is reaffirmed¹⁶ in General Comment No. 14) stresses that 'persons with disabilities should be provided with the same level of medical care *within the same system* as other members of society.'¹⁷ Therefore, other CESCR comments on the right to health apply with equal force to persons with disabilities.

The article 12 right to health includes *inter alia* 'the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as

¹⁴ CRPD, *supra* note X, at art. 2.

¹⁵ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 18 (emphasis added).

¹⁶ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 26.

¹⁷ CESCR General Comment No. 5: persons with disabilities (1994), para. 34 (emphasis added).

the right to be free from torture, non-consensual medical treatment and experimentation.’¹⁸ It also extends to underlying determinants of health, including access to sexual and reproductive health education and information.¹⁹

The ICESCR right to health in all forms and at all levels is characterised by four ‘interrelated and essential elements’: availability, accessibility, acceptability and quality.²⁰ Accessibility in particular is relevant to the SRH needs of women and other persons with disabilities. This element requires that all health facilities, goods and services be accessible to everyone without discrimination,²¹ and it has four overlapping dimensions:

- ‘Non-discrimination: health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.
- Physical accessibility: ‘health facilities, goods and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized populations, such as . . . women, children . . . persons with disabilities . . . Accessibility further includes adequate access to buildings for persons with disabilities.
- Economic accessibility (affordability): health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.
- Information accessibility: accessibility includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality.’²²

UNAIDS, the WHO and OHCHR have identified insufficient access to appropriate HIV prevention and support services as one of the key factors putting PWDs at increased risk for HIV infection.²³ PWDs may be turned away from HIV education programmes or overlooked by outreach workers because of misperceptions that they are not sexually active or engaging in other risky behaviour;²⁴ this is discriminatory and violates the right to health under the ICESCR.

The catalogue of examples in article 12(2) is non-exhaustive and merely provides guidance in defining the action to be taken by States in realising its responsibilities under article 12.²⁵

The CESCR’s General Comment No. 14 on the right to health specifically addressed strategies to realise women’s right to health and the need to eliminate discrimination against all women, including women with disabilities. The Committee urged states to develop and implement a comprehensive national strategy to promote women’s rights to health, including policies to provide access to sexual and reproductive services. The Committee stated: ‘[t]he realization of women’s right to health requires the removal of all barriers interfering with

¹⁸ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 8.

¹⁹ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 11.

²⁰ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 12.

²¹ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 12(b).

²² CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. (12)(b)(i)-(iv).

²³ UNAIDS, WHO & OHCHR Policy Brief: Disability and HIV, pg. 2 (2009).

²⁴ UNAIDS, WHO & OHCHR Policy Brief: Disability and HIV, pg. 3 (2009).

²⁵ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 13.

access to health services, education and information, including in the area of sexual and reproductive health.²⁶

The Committee put forth as a specific legal obligation for States Parties:

‘States should refrain from limiting access to contraceptives and other means of maintaining sexual and reproductive health, from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information, as well as from preventing people’s participation in health-related matters.’²⁷

This is particularly relevant for women with disabilities, as reports indicate these women are routinely turned away from places offering sexual and reproductive health services when they seek help, often told that they should not become pregnant or being reprimanded because they want to have a child or enjoy sexual relationships.²⁸

All members of society, including health professionals, organisations and the private business sector, have responsibilities regarding the realisation of the right to health; the Committee therefore has said that State parties should ‘provide an environment which facilitates the discharge of these responsibilities.’²⁹ CESCR has particularly stressed the importance of ensuring that not only the public health sector but also private health practitioners comply with the principle of non-discrimination in relation to persons with disabilities.³⁰

CEDAW articulates its right to health in article 12, which reads:

1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.
2. Notwithstanding the provisions of paragraph 1 of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

In its General Comment No. 24, the Committee on the Elimination of the Discrimination against Women affirmed that access to health, including reproductive health, is a basic right under CEDAW,³¹ and that special attention should be given to the health needs and rights of vulnerable and disadvantaged women like women with disabilities.³²

The CEDAW Committee urges all States parties to ensure that all women and girls have the right to sexual health information, education and services without prejudice and discrimination.³³

States parties are requested to report to the CEDAW Committee on measures taken to make health care services acceptable to women.³⁴ Acceptable services are ‘those which are

²⁶ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 21.

²⁷ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 34.

²⁸ WHO & UNFPA, PROMOTING SEXUAL AND REPRODUCTIVE HEALTH FOR PERSONS WITH DISABILITIES 10 (2009).

²⁹ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 42.

³⁰ CESCR General Comment No. 14: the right to the highest attainable standard of health (2000), para. 26.

³¹ CEDAW General Comment No. 24: women and health (1999), para. 1.

³² CEDAW General Comment No. 24: women and health (1999), para. 6.

³³ CEDAW General Comment No. 24: women and health (1999), para. 18.

delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives.³⁵ Forced sterilisation is specifically mentioned as a prohibited form of coercion that violates women's rights to informed consent and dignity.³⁶

The Committee on the Rights of the Child specifically addresses the sexual and reproductive health needs of children with disabilities in its General Comment No. 9. Observing that children with disabilities are often faultily perceived as being non-sexual,³⁷ the Committee notes that adolescents with disabilities face multiple challenges and risks related to relationships and reproductive health. The Committee 'recommends that States parties provide adolescents with disabilities with adequate, and where appropriate, disability specific information, guidance and counselling' related to these topics.³⁸

The Committee also noted that it was 'deeply concerned' about the prevailing practice of forced sterilisation of children, especially girls, with disabilities. Forced sterilisation 'seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects.'³⁹ The Committee therefore urged States parties to legally prohibited the forced sterilisation of children on grounds of disability.⁴⁰

Freedom from torture and other cruel, inhuman or degrading treatment or punishment

The prohibition against torture is a *jus cogens* norm of customary international law,⁴¹ meaning that it is nonderogable and binding on all states regardless of whether they are signatories to a treaty that bans the practice. However, customary international law is often very difficult to litigate, and the lack of a supporting textual jurisprudence makes proving a specific act (for example, forced sterilisation) falls under the category of torture an arduous task. Therefore, if a country is a signatory to one of the following treaties, it is a much better litigation strategy to argue based on the country's treaty obligations rather than under customary international law.

The Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT) proscribes torture in the strongest terms:

³⁴ See CEDAW Committee: *Concluding Observations: Hungary*, para. 8, U.N. Doc. CEDAW/C/HUN/CO/6 (2007); CEDAW Committee, *Concluding Observations: Czech Republic*, para. 23, U.N. Doc. CEDAW/C/CZE/CO/3 (2006).

³⁵ CEDAW General Comment No. 24: women and health (1999), para. 22.

³⁶ CEDAW General Comment No. 24: women and health (1999), para. 22.

³⁷ Committee on the Rights of the Child, General Comment No. 9: rights of children with disabilities (2006), para. 42(e).

³⁸ Committee on the Rights of the Child, General Comment No. 9: rights of children with disabilities (2006), para. 59. The Committee also recommends that States parties fully take into account the Committee's general comments No. 3 (2003) on HIV/AIDS and the rights of the child and No. 4 (2003) on adolescent health and development.

³⁹ Committee on the Rights of the Child, General Comment No. 9: rights of children with disabilities (2006), para. 60.

⁴⁰ Committee on the Rights of the Child, General Comment No. 9: rights of children with disabilities (2006), para. 60.

⁴¹ Erika de Wet, *The Prohibition of Torture as an International Norm of jus cogens and its Implications for National and Customary Law*, 15 EUR. J. INT'L L. 97, 97 (2004).

'No exceptional circumstances whatsoever, whether a state of war or a threat of war, internal political instability or any other public emergency, may be invoked as a justification of torture.'⁴²

The CRPD similarly prohibits torture under article 15.

1. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
2. States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

An interim report presented to the General Assembly on behalf of the Special Rapporteur of the Human Rights Council on torture and other cruel, inhuman or degrading treatment or punishment in 2008⁴³ expanded on both these definitions of torture in relation to persons with disabilities.

The Special Rapporteur, Manfred Nowak, expressed concern that medical experimentation and intrusive and irreversible medical treatments performed without the consent of persons with disabilities, including sterilisation and abortion, continue to go unnoticed or to be justified, and thereby escape being labelled as torture or other cruel, inhuman or degrading treatment or punishment.⁴⁴

The Special Rapporteur suggested that the application of article 15 of the CRPD can be informed by the definition of torture in article 1 of CAT:

'For an act against or an omission with respect to persons with disabilities to constitute torture, the four elements of the Convention definition — severe pain or suffering, intent, purpose and State involvement — need to be present. Acts falling short of this definition may constitute cruel, inhuman or degrading treatment or punishment under article 16 of the Convention against Torture.'⁴⁵

An entirely appropriate medical treatment may cause severe pain or suffering, but not constitute torture because it lacks the required purpose or intent. On the other hand, medical treatments of an intrusive and irreversible nature, especially when they lack a therapeutic purpose, may constitute torture or ill-treatment if they are performed without the free and informed consent of the patient.⁴⁶

The Special Rapporteur concluded that the requirement of intent can be effectively implied where a person has been discriminated against on the basis of disability.⁴⁷ This is especially relevant in the context of medical procedures performed on persons with disabilities, where serious human rights violations and discrimination may be 'masked as "good intentions"' on

⁴² CAT, art. 2(2).

⁴³ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, U.N. Doc. A/63/175, July 28, 2005.

⁴⁴ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, paras. 40-41, U.N. Doc. A/63/175, July 28, 2005.

⁴⁵ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, para. 46, U.N. Doc. A/63/175, July 28, 2005.

⁴⁶ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, para. 47, U.N. Doc. A/63/175, July 28, 2005.

⁴⁷ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, para. 49, U.N. Doc. A/63/175, July 28, 2005.

the part of the patient's family and/or health professionals.⁴⁸ This is often the case with the so-called Ashley treatment and compulsory sterilisation.

The interim report specifically mentioned forcible sterilisation and abortions without free and informed consent of women and girls with disabilities as a practice of concern to the Special Rapporteur:

'Innumerable adults and children with disabilities have been forcibly sterilized as a result of policies and legislation enacted for that purpose. Persons with disabilities, and particularly women and girls, continue to be subjected to forced abortion and sterilization without their free and informed consent inside and outside institutions, a practice in relation to which concern has been expressed. The Special Rapporteur notes that under article 23(c) of CRPD States parties have an obligation to ensure that "persons with disabilities, including children, retain their fertility on an equal basis with others" and to ensure their right to decide freely and responsibly on the number and spacing of their children (art. 23(b)).'⁴⁹

Though the Special Rapporteur referred to article 23 of the CRPD (respect for home and the family) instead of article 15 (freedom from torture or cruel, inhuman or degrading treatment or punishment), the paragraph is under a section of the report titled '*Applying the torture and ill-treatment protection framework to persons with disabilities.*' Together with the fact that the practice was mentioned in an interim report by the Special Rapporteur on torture, this strongly suggests that the practice is considered to be torture or cruel, inhuman or degrading treatment under international law. The Committee Against Torture has also raised forced sterilisation as a concern in its concluding observations.⁵⁰

In order for an individual to give free and informed consent to a medical procedure, information about the purpose, risks, benefits and alternative treatments must be provided in a manner that is understandable to her. The WHO explains that "information must be communicated to the patient in a way appropriate to the latter's capacity for understanding, minimising the use of unfamiliar technical terminology. If the patient does not speak the common language, some form of interpreting should be available."⁵¹ The CRPD recognises that "communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology."⁵² In addition, the International Federation of Gynaecology and Obstetrics (FIGO) Guidelines Regarding Informed Consent specifically note that the difficulty or time consuming nature of providing such information to certain patients does not absolve medical providers from working to satisfy the criteria for informed consent.⁵³

⁴⁸ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, para. 49, U.N. Doc. A/63/175, July 28, 2005.

⁴⁹ Interim report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, para. 60, U.N. Doc. A/63/175, July 28, 2005.

⁵⁰ See Committee against Torture, concluding observations on the third periodic report of the Czech Republic (CAT/C/CR/32/2, paras. 5(k) and 6(n)) and on the fourth periodic report of Peru (CAT/C/PER/CO/4, para. 23).

⁵¹ WHO, A Declaration on the Promotion of Patients' Rights in Europe, art. 2.4.

⁵² CRPD, art. 2.

⁵³ FIGO, *Guidelines regarding informed consent*, 101 INT'L J. GYNECOLOGY & OBSTETRICS 219, 219 (2008).

FIGO Guidelines on Contraceptive Sterilization also recognise that forced sterilisation is an act of violence.⁵⁴ These guidelines are not legally binding, but they represent a global ethical consensus of obstetricians and gynaecologists rooted in human rights law and medical best practices.

The ICCPR prohibits torture using much the same language as the CRPD. Article 7 reads:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

The Human Rights Committee clarified in its General Comment No. 20 on the prohibition of torture that article relates not only to acts that cause physical pain, but also to acts that cause mental suffering. It emphasized that article 7 particularly protects children, students and patients in teaching and medical institutions.⁵⁵ Special protection is also necessary for persons incapable of giving valid consent and anyone under any form of detention, including in mental health institutions.⁵⁶

Forced abortions and forced sterilisation violates article 7 of the ICCPR. As part of assessing compliance with article 7, the HRC requests that States parties provide the Committee with information on measures to prevent forced abortion or forced sterilisation, as well as measures of protection and legal remedies for women whose rights have been violated under article 7 in this way.⁵⁷

Though not technically categorised as freedom from torture, the Committee on the Rights of the Child has also addressed the issue of forced sterilisation of girls with disabilities. The Convention on the Rights of the Child requires States Parties to protect children from 'all forms of physical or mental violence'.⁵⁸ The Committee takes the position that there is no room for any level of legalized violence against children. In General Comment No. 13, the Committee characterizes forced sterilisation, particularly against girls, as a particular form of physical violence to which children with disabilities are subjected.⁵⁹ Forced sterilisation is therefore a violation of article 19(1) of the Convention on the Rights of the Child.

Access to justice

According to OSISA's report on disability rights in southern Africa, women and children with disabilities experience high levels of sexual abuse and rape.⁶⁰ Persons with intellectual

⁵⁴ FIGO, *Female Contraceptive Sterilization*, <http://www.who.org/files/figo-corp/FIGO%20-%20Female%20contraceptive%20sterilization.pdf>.

⁵⁵ Human Rights Comm., General Comment No. 20: prohibition of torture or cruel, inhuman or degrading treatment or punishment (1992), para. 5.

⁵⁶ Human Rights Comm., General Comment No. 20: prohibition of torture or cruel, inhuman or degrading treatment or punishment (1992), para. 7.

⁵⁷ Human Rights Comm., General Comment No. 28: equality of rights between men and women (2000), para. 11. *See also* Human Rights Committee, concluding observations on the fourth periodic report of Peru (CCPR/CO/70/PER, para. 21); on the second periodic report of the Czech Republic (CCPR/C/CZE/CO/2, para. 10); on the second periodic report of Slovakia (CCPR/CO/78/SVK, paras. 12 and 21), and on the fourth periodic report of Japan (CCPR/C/79/Add.102, para. 31).

⁵⁸ CRC, art. 19(1).

⁵⁹ Comm. on the Rights of the Child, General Comment No. 13: the right of the child to freedom from all forms of violence (2011), para. 23(a).

⁶⁰ Hermien Kotze, OSISA, *Status of Disability Rights in Southern Africa*, pg. 30.

disabilities and those in specialized institutions, schools or hospitals are additionally at particularly high risk.⁶¹ This is at least in part due to a widespread myth across the region that sex with a disabled person will cure AIDS – an extension of the so-called ‘virgin cure’ and based on the common assumption that persons with disabilities are sexually inactive for life.⁶² PWDs also make relative “easy targets” for would-be rapists: a woman or girl with a physical disability may not be able to flee, while a blind victim cannot identify her attacker after the fact, etc.⁶³

The high incidence of sexually violent attacks committed against women with disability highlights the special need for these women to have effective access to sexual and reproductive health information and services; it is crucial to the realisation of their human rights that they are able to seek and receive timely and appropriate care in the aftermath of such attacks, which put them at increased risk of STI/HIV infection, unwanted pregnancy and other injuries.

When PWDs experience sexual violence and other rights violations, including those mentioned in this chapter, they often encounter serious discrimination and difficulties in accessing the justice system. As a result, many perpetrators of crimes against PWDs are never brought to justice. Persons with intellectual disabilities in particular may be ignored by police if they claim they have been the victim of an assault or other violation, based on a perception that their disability makes them incapable of giving credible information about what has happened to them. PWDs may also be formally or informally barred from giving evidence or testimony at trial, further hindering investigations and prosecutions of crimes committed against them. These structural barriers to the legal system in the process of seeking remedy for violations of their human rights, amounts in and of itself to a violation of their right to access to justice.

Miscellaneous.

Many of the issues relating to forced sterilisation, abortion and the Ashley Treatment raise the complex question of how much authority guardianship over a PWD can or should confer about matters of health.

- Possible issues for discussion:
 - o Adolescents with disabilities and SRH vs. adults with disabilities and SRH
 - o Physical vs. intellectual/psychosocial disabilities
 - o Are SRH decisions qualitatively different from other kinds of health decisions (e.g. childhood vaccinations, cancer treatments)? Why?
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⁶¹ UNAIDS, WHO & OHCHR Policy Brief: Disability and HIV, pg. 2-3 (2009).

⁶² Hermien Kotze, OSISA, Status of Disability Rights in Southern Africa, pg. 30.

⁶³ Hermien Kotze, OSISA, Status of Disability Rights in Southern Africa, pg. 30.

Right to education

Case example: Discrimination in education

The Western Cape High Court of South Africa, in *Western Cape Forum for Intellectual Disability v South Africa*, addressed whether the exclusion of children with severe or profound intellectual disabilities from schools violated their *inter alia* right to a basic education. The government claimed it was necessary due to lack of resources. The court rejected this argument, pointing out that no extra funds were necessary – only the fair distribution of available funds among all children. On a finding that the government had singled out the children with severe intellectual disabilities for less favourable treatment, the court found the children's right to a basic education had been infringed.

Children with disabilities have the same right to education as all children. They are additionally entitled to the accommodations and assistance necessary to facilitate access to educational opportunities in an equal manner as other children.

The right to education may be implicated in cases where children with disabilities are denied access to schools, placed in inappropriate educational settings or do not receive reasonable accommodation in the classroom. Under international law, the right to education encompasses much more than simple entry into a classroom: a wide array of arguments can be made based on international law obligations related to education-based rights.

Article 24 of the Convention on the Rights of Persons with Disabilities recognizes the right of persons with disabilities to education.¹ While acknowledging that the right is subject to progressive realization, the article goes quite in-depth with regard to the obligations of States Parties:

2. In realizing this right, States Parties shall ensure that:

- (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
- (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
- (c) Reasonable accommodation of the individual's requirements is provided;
- (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:

- (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
- (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
- (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.²

¹ CRPD, *supra* note X, at art. 24.

² *Id.*

The article additionally mandates States to employ teachers qualified in sign language and/or Braille and to train professionals and staff at all levels of education in disability awareness and the use of appropriate means of communication and materials to support PWDs.³ States must also ensure reasonable accommodation to PWDs to facilitate their access to tertiary education and vocational training.⁴

According to the Committee on the Rights of Persons with Disabilities, the duty to provide reasonable accommodation in education is 'immediately applicable and not subject to progressive realization,' unlike other rights in the Convention.⁵ Failure to provide reasonable accommodation constitutes discrimination under article 5(3) of the child's article 24 right to education.

The Convention on the Rights of the Child specifically includes disability as a prohibited ground of discrimination⁶ and has three separate articles related to education. Article 28 provides for the progressive realization of the right to education, including compulsory and free primary education for all.⁷ Article 29 addresses the aims of education for children. These are:

- (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;
- (b) The development of respect for human rights and fundamental freedoms, and for the principles enshrined in the Charter of the United Nations;
- (c) The development of respect for the child's parents, his or her own cultural identity, language and values, for the national values of the country in which the child is living, the country from which he or she may originate, and for civilizations different from his or her own;
- (d) The preparation of the child for responsible life in a free society, in the spirit of understanding, peace, tolerance, equality of sexes, and friendship among all peoples, ethnic, national and religious groups and persons of indigenous origin;
- (e) The development of respect for the natural environment.⁸

States Parties are urged to formally incorporate these principles into their education policies and legislation at all levels.⁹

In article 23, which specifically addresses the rights of children with disabilities, the Convention obligates States Parties to provide assistance to disabled children to allow for effective access to *inter alia* education. This assistance should be 'free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child.'¹⁰

In its first General Comment, the Committee on the Rights of the Child expanded on article 29(1) and the aims of education, explaining that the type of education envisioned in that article 'goes far beyond formal schooling to embrace the broad range of life experiences and learning processes which enable children, individually and collectively, to develop their

³ *Id.* at art. 24(4).

⁴ *Id.* at art. 24(5).

⁵ Committee on the Rights of PWDs, Concluding Observations, Spain 2012, para. 44.

⁶ CRC, *supra* note X, at art. 2(1).

⁷ *Id.* at art. 28(1)(a).

⁸ *Id.* at art. 29.

⁹ CRC General Comment No. 1 (2001): Article 29(1): the aims of education, para. 17.

¹⁰ CRC, *supra* note X, at art. 23(3).

personalities, talents and abilities and to live a full and satisfying life within society.’¹¹ The Committee has stated that it is especially important that the education of children with disabilities includes the ‘strengthening of positive self-awareness,’ ensuring that each child feels he or she is ‘respected by others as a human being without any limitation of dignity.’¹²

Overt or hidden discrimination on any of the article 2 grounds (including disability) can undermine or destroy the capacity of a child to benefit from educational opportunities otherwise granted to them. The Committee explained:

While denying a child’s access to educational opportunities is primarily a matter which relates to article 28 of the Convention, there are many ways in which failure to comply with the principles contained in article 29(1) can have a similar effect. . . . Discrimination against children with disabilities is also pervasive in many formal educational systems and in a great many informal educational settings, including in the home. . . . All such discriminatory practices are in direct contradiction with the requirements in article 29(1)(a) that education be directed to the development of the child’s personality, talents and mental and physical abilities to their fullest potential.¹³

Classroom arrangements which limit the benefits children with disabilities can obtain from the opportunities offered, or environments which discourage disabled children’s participation, may therefore constitute violations of article 29(1), even if they facially satisfy article 28. These situations may still amount to a denial of educational opportunities under the Convention on the Rights of the Child.

As recognized by the Committee on the Rights of the Child and the Committee on Economic, Social and Cultural Rights, the goal of educating children with disabilities should be inclusive education.¹⁴ However, this does not simply entail placing children with disabilities into mainstream classrooms. Rather:

[a]t its core, inclusive education is a set of values, principles and practices that seeks meaningful, effective, and quality education for all students, that does justice to the diversity of learning conditions and requirements not only of children with disabilities, but for all students. . . . *It is important to understand that inclusion should not be understood nor practiced as simply integrating children with disabilities into the regular system regardless of their challenges and needs.*¹⁵

Failure to re-evaluate and develop schools’ curricula to meet the needs of all children, or to modify training programmes for teachers and other personnel in the educational system, may result in impartial or faulty implementation of inclusive education. This may in turn result in a classroom atmosphere that is not conducive to the holistic development of the personalities, talents and mental and physical abilities of children with and without disabilities, and failure to conform with the principles of article 29(1).

At the same time, the extent of inclusion within the general education system may legitimately vary. Where fully inclusive education is not feasible in the immediate future, a ‘continuum of services and programme options’ must be maintained by State Parties to the CRC.¹⁶ The manner and form of inclusion must be determined by the individual educational

¹¹ CRC General Comment No. 1 (2001): Article 29(1): the aims of education, para. 2.

¹² CRC General Comment No. 9 (2006), para. 64.

¹³ CRC General Comment No. 1 (2001): Article 29(1): the aims of education, para. 10.

¹⁴ See CRC Committee, General Comment No. 9 (2006), para 66; ESCR Committee, General Comment No. 5 (1994), para. 35.

¹⁵ CRC Committee, General Comment No. 9 (2006), para 67.

¹⁶ CRC Committee, General Comment No. 9, para. 66.

requirements of each child, since some children with disabilities require a kind of support which may not be readily available in the regular school system. The best interests of the child (CRC art. 3) should outweigh any other consideration.¹⁷

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities also display a preference for inclusive education.¹⁸ However, where special education is necessary due to an inability of the general school system to meet the needs of students with disabilities, the Rules emphasize that it should be aimed at preparing students for education in the general school system, and the quality of the education should reflect the same standards as general education.¹⁹ Additionally, students with disabilities should be 'afforded the same portion of educational resources as students without disabilities.'²⁰ The Committee on the Rights of the Child has also addressed the issue of adequate resource allocation to education programmes for children with disabilities.²¹

To the extent that students with disabilities may be placed in separate educational institutions, the Committee on the Rights of Persons with Disabilities has stressed the importance that parents have the ability to 'swiftly and effectively' appeal decisions to segregate their children in this way.²²

Articles 13 and 14 of the ICESCR also address the right to education. Article 13(2) specifies disparate obligations for different levels of education. However, the Committee on Economic, Social and Cultural Rights has declared that education at all forms and at all levels must exhibit the 'interrelated and essential' features of *availability, accessibility, acceptability* and *adaptability*.²³ The feature most relevant to children with disabilities is *accessibility*.

- **Accessibility:** educational institutions and programmes have to be accessible to all students on a non-discriminatory basis. There are three overlapping aspects of accessibility.
 - **Non-discrimination:** education must be accessible to all, especially the most vulnerable groups (including students with disabilities), in law and in fact, without discrimination on any of the prohibited grounds.
 - **Physical accessibility:** education must be within safe physical reach of students. This could be accomplished through physical attendance at a school located in a convenient geographic location, or else through modern technology (e.g. access to a 'distance learning' programme).
 - **Economic accessibility:** education must be affordable to all. This requirement is subject to the differential wording of article 13(2): whereas primary education must be 'free to all,' secondary and higher education must only be made 'available' and/or 'equally accessible' (though States are required to progressively introduce free secondary and higher education).²⁴

¹⁷ CRC Committee, General Comment No. 9, para. 30.

¹⁸ Standard Rule 6.

¹⁹ Standard Rule 6(8).

²⁰ Standard Rule 6(8).

²¹ CRC Committee, Concluding Observations, The Gambia (2001), para. 50.

²² CRPD Committee, Concluding Observations, Spain 2012, para. 44(d).

²³ ESCOR Committee, General Comment No. 13 (1999), para. 6.

²⁴ ESCOR Committee, General Comment No. 13 (1999), para. 6(b).

ICESR article 13(2)(b) presents technical and vocational education (TVE) as part of secondary education. Under the ICESR, TVE also forms part of the right to work (art. 6(2)). While TVE may play a particular important role in secondary education, therefore, the ESCR Committee recognizes that TVE 'forms an integral element of all levels of education.'²⁵ According to the UNESCO Convention on Technical and Vocational Education, TVE consists of 'all forms and levels of the educational process involving, in addition to general knowledge, the study of technologies and related sciences and the acquisition of practical skills, know-how, attitudes and understanding relating to occupations in the various sectors of economic and social life.'²⁶

As such, the ESCR Committee considers that, in the context of the ICESCR's non-discrimination and equality provisions, the right to TVE consists of programmes which promote the TVE of women and girls, persons with disabilities and other disadvantaged groups.²⁷

The Committee on the Rights of the Child agrees. It has noted that, in countries where compulsory education does not extend beyond primary school, vocational training beyond elementary school should be mandatory for children with disabilities, and governments must establish policies and allocate sufficient funds to support such vocational training.²⁸

²⁵ CESCR Committee, General Comment No. 13 (1999), para. 15.

²⁶ UNESCO Convention on Technical and Vocational Education, art. 1(a).

²⁷ CESCR Committee, General Comment No. 13 (1999), para. 16.

²⁸ CRC Committee, General Comment No. 9 (2006), para. 69.

