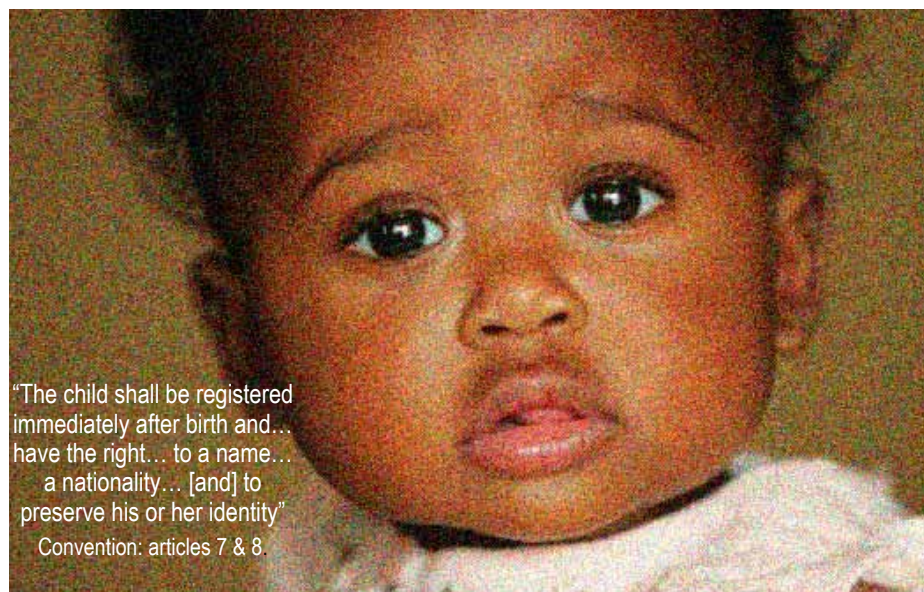


THE UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

AND IMPLICATIONS FOR CLINICAL PRACTICE, POLICY AND RESEARCH

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"The child shall be registered immediately after birth and... have the right... to a name... a nationality... [and] to preserve his or her identity"
Convention: articles 7 & 8.

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The *United Nations (UN) Convention on the Rights of the Child* (Convention) and subsequent related documents have the potential for greatly improving the lives of children (birth to 18 years of age, but dependent on culture) in several dimensions, offering protection from abuse, strengthening children's relationship with families and ensuring the realization of individual potential. These documents go well beyond having implications for governments and should be considered in relation to all professional activities that impinge on the lives of children including clinical practice, research, participation and education.

Currently, there is tension between the community of "disabled" and those with "mental disorders" with significant implications for progress in child related human rights. Is a mental disorder a "disability"? Will inclusion of those with mental disorders weaken or distort advocacy for those with non-mental disorder disabilities? At a time when there are great opportunities for advocacy this issue needs to be addressed because in the current era it may be one of the greatest barriers to the promotion of the needs of those with mental disorders in the context of human rights as put forth in the Convention and the recently adopted *UN Convention on the Rights of People with Disabilities* (CRDP). The issues of exclusion and disenfranchisement are common to all with disabilities and certainly to those with mental disorders.

The historical understanding of children and childhood must be appreciated to realize how children, in particular, can suffer drastic consequences as a result of being considered disabled (Hibbard & Desch, 2007). In the modern history of civilization children were seen as property (Slee, 2002). The role of children was to increase the productivity of the family and propagate to continue the family line (Slee, 2002). There was, until the past century, no concept of a developing child with potentials that could be enhanced or thwarted by environmental or attitudinal factors. There was little understanding of a developmental trajectory for children and that they were not simply little adults. Lastly, in many cultures it was felt that *children should be seen and not heard* and that they did not have a claim on the right of inclusion. Both because of a better scientific understanding of child development and the evolution of social thinking, children are now viewed differently by many, but certainly not by all segments of society. However, the potential of children with disabilities, for the most part, continues to be ignored: "...widespread underestimation of the abilities and potential of children with disabilities creates a vicious cycle of under-expectation, under-achievement and low priority in the allocation of resources." www.unicef-irc.org

Emotional and behavioral problems affect between 10% and 20% of children worldwide (Belfer, 2008). Recognizing childhood emotional and behavioral problems in the context of disability rights, remains a challenge and, to date, has not had the prominence warranted (Stewart-Brown, 2003). Data on the cost to society of mental disability in children is yet to be fully calculated, but the studies that are available show dramatic costs, comparable to those of other disabilities and with equal issues related to participation in society. The emotional and physical disability resulting from exposure to war, famine, disasters and HIV/AIDS is nearly incalculable. The approaches to understanding and intervening in these situations not only involve concerns with the rights of children, in the usual framework, but extend to those who seek to engage in research with these vulnerable populations. This chapter attempts to focus a light on the barriers which

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children with disabilities continue to face in being considered active members of society, and the need for responsible research.

CONSEQUENCES OF DISABILITY

In many countries, children with disabilities are placed in institutions at birth or as toddlers and remain there until death. All available data show that children in institutions do far worse socially, educationally, medically and psychologically than children raised in supportive community settings (Groce & Paeglow, 2005). Human Rights Watch found that the death rate among institutionalized children with disabilities was almost twice that of the general population and of children kept at home. In some institutions in some countries the mortality rate exceeds 75% (Human Rights Watch, 2001).

According to the United Nations and UNICEF, girls with disabilities are twice or three times more likely to experience sexual and physical abuse than their non-disabled peers. Where the ability to contribute economically to family survival is critical, children with disabilities have little value other than as objects displayed for pity or money. The most common employment around the world for disabled people is begging (Groce, 1999). Isolation both self-imposed and socially created is common, particularly for those who look different.

CONCEPT OF PARTICIPATION

Approaches to clinical care for people with disabilities are too often conceived from a *deficit model* focusing on individual impairment. This has consequences for how the person is viewed and unreasonably limits expectations. The Convention (article 12) redefines the role of children in society as participants and, through their participation, as critical contributors to their own health and that of the community in which they live. If the clinician and policymaker move from a deficit model to the concept of *maximizing participation* and focus on the barriers faced by people with disabilities in seeking full participation, then many opportunities for creative programming are opened. It requires a considerable shift in the mindset of clinicians and policymakers but once adopted can be seen as freeing up opportunities or identifying barriers that can readily be overcome.

The efforts to include children and adolescents in mainstream education have met with varying levels of success. Low and middle income countries, as defined by the World Bank, have demonstrated some of the more innovative approaches, often out of necessity.

The World Health Organization has attempted through the International Classification of Impairments, Disabilities and Handicaps (ICIDH-2) to disseminate a model for professionals to use to approach care for people who have impairments from the perspective of participation. The ICIDH-2 covers three dimensions of disability:

- Impairment in bodily functions and structures
- Limitation in activity, and
- Restriction in participation.

This classification recognizes that someone with an impairment may or may not have a limitation in activity or even a disability, depending on the environment

RIGHTS OF THE CHILD

The first United Nations statement devoted exclusively to the rights of children was the Declaration on the Rights of the Child, adopted in 1959. This was a moral rather than a legally binding document. In 1989 the legally binding Convention on the Rights of the Child was adopted by the United Nations. In 54 articles the Convention incorporates the whole spectrum of human rights—civil, political, economic, social and cultural—and sets out the specific ways these should be ensured for children and young people. In May 2000, two Optional Protocols, one on the involvement of children in armed conflict and a second on the sale of children, child prostitution and child pornography, were adopted to strengthen the provisions of the Convention in those areas. The Convention on the Rights of the Child is the most endorsed human rights treaty in the world, ratified by all but two countries. View the Convention and related documents by clicking on the picture below.





“...the child who is capable of forming his or her own views [has] the right to express those views [and] the right to freedom of... thought, conscience and religion.”

Convention: articles 12-14.

Photo : <http://syinghana.com/?p=137>



Click on the picture to view a short animation explaining the Convention to children (by the Children's Rights Alliance) (www.childrensrights.ie)

Table J.7.1 The United Nations Convention on the Rights of the Child summarized according to article (Carlson, 2001).

Principles	Provisions	Protection	Participation
A2: Non-discrimination	A5: Guidance	A19: Abuse and neglect	A13: Expression
A3: Best interest	A7: Name/nationality	A21: Adoption	A14: Thought
A6: Survival and development	A8: Identity	A22: Refugee	A15: Association
A12: Respect for child's views	A9: Parent separation	A32: Labor	A17: Information
	A16: Privacy	A33: Drugs	
	A18: Responsibilities	A34: Sexual exploitation	
	A24: Health	A35: Abduction	
	A25: Social security	A37: Torture and deprivation of liberty	
	A27: Standard of living	A38: Armed conflict	
	A28 and A29: Education	A39: Rehabilitative care	
	A31: Leisure	A40: Juvenile justice	

human rights legislation (in fact, in the Convention, children with disabilities were specifically included), but because the moral platform which is used to interpret such documents has been skewed to leave out certain populations. The social model of disability, from which the Convention and CRDP are derived, places the obligation for inclusion squarely back on the shoulders of society. In this model, disability is not inherent in the person but rather, occurring with the interaction between a person with impairment and societal, attitudinal and environmental barriers.

In a way, the existence of the CRDP points to the fact that it is (again) the larger philosophical construct of the omnipotent “we” which is the problem. Since the Enlightenment, as previously marginalized segments of society have demanded and realized their voice, the conception of who “we” are has gradually expanded. Sixty years after the adoption of the Universal Declaration on Human Rights, thanks largely to the persistence of the disability rights movement (whose slogan is “nothing about us without us”), there is recognition that disability is part of the human experience.

As law professor Amita Dhanda writes, “It is my view that the Convention on the Rights of People with Disabilities has done the following for persons with disabilities: it has signaled the change from welfare to rights; introduced the equality idiom to grant both the same and different to persons with disabilities; recognized autonomy with support for persons with disabilities and most importantly made disability a part of the human experience” (Dhanda & Narayan, 2007). Whether the CRDP and the growing disability rights movement will give a voice to children remains to be seen.

Rights-based approaches to children with disabilities

It is an indictment of society that children and adolescents have not seen meaningful inclusion and participation when they have been born with impairments or suffered disability. Remedies have been proposed, and in some cases demonstrated to be effective, but their implementation is patchy and often not sustained. Two prominent examples of initiatives to address the lack of voice for the rights of children with disabilities are the Guardianship Councils in Brazil and the Social Charter of the European Union. These are very different approaches but both draw heavily on legal remedies and due process with respect for the plaintiff.

Guardianship Councils

The 1988 Federal Brazilian Constitution emphasized popular participation in governance. Municipal Participatory Administrative Councils were formed. The child rights perspective embedded in the authorizing legislation and implementation has transformed a disadvantaged population of children into a population of citizens whose current and future rights should be respected (Duarte et al, 2007; Rizzini et al, 2003). The authorizing legislation covers all children under the age of 21 and, notably, does not single out one *at risk* group. The legislation is broad but focuses on the entitlement to rights. The legislation determined that children’s rights will be guaranteed through the activities of municipal Administrative Councils. The Brazilian Child and Adolescent Rights Act mandates that every one of approximately 5,700 Brazilian municipalities should have two Municipal Child Councils: a Child Rights Council and a Child Guardianship Council. In addition each state should have one State Child Rights



Click on the picture to view a video on dealing constructively with disability discrimination in sport.



“No child shall be subjected to arbitrary or unlawful interference with his or her privacy...nor to unlawful attacks on his or her honour and reputation.”

Convention: article 16.

Arab water carrier girls, Egypt (Brooklyn Museum)

Council. The Child Rights Council has the responsibility for addressing child and adolescent rights at the macro level. The Guardianship Councils ensure that children in need or at risk receive the best possible assistance. Their task is to make referrals and guarantee the delivery of services, but not act as a provider. Access to the Guardianship Councils can be by the children themselves, parents or a wide range of other interested parties.

European Social Charter

The European Social Charter (Council of Europe) is a rights-based document that can and has been applied in the case of apparent discrimination of people with disabilities. A notable example is the successful appeal by Autism Europe to the European Committee of Social Rights complaining that in France “...children and adults with autism do not, and are not likely to, effectively exercise in sufficient numbers and to an adequate standard, their right to education in mainstream schooling or through adequately supported placements in specialized institutions that offer education and related services.” In essence, the complaint alleged that France is not taking enough action, as required under the revised European Social Charter, to secure children and adults with autism a right to education as effective as that of all the other children. While this is a specific example that has led to remediation, the articles themselves serve as a model. The Code of Social Action states that “...whenever the aptitudes of the person with a disability and the capabilities of the family so allow, ensure access to the minor or adult with disability to those institutions open to the whole population.” “Social and medico-social action shall...promote the autonomy and protection of individuals...prevent exclusion and correct its effects. It shall be based on continuous evaluation and needs and of expectations...in particular of those people with disabilities.” “...action shall respect the equal dignity of all human beings...” It will be interesting to see if and how models such as these gain uptake in implementation of the new Convention on the Rights of People with Disabilities.

Paradigm shifts for clinicians

“Integrating the principles of children’s rights, equity and social justice into practice will require a fundamental shift in the education of child health professionals at all levels of training.” (Waterston & Goldhagen, 2008). If a high priority is to be given to providing rights-based services to children with disabilities, it will be increasingly necessary to engage, train and prepare non-government organizations, professionals, parents of children with disabilities and children with disabilities themselves to work together to effect change. Professional training programs today still focus on medicalization of disability. The focus on specialization for working with differing populations of children with disabilities thwarts the desire to lessen discrimination in services and the participation of children in the mainstream of society. Professional concern goes beyond clinical care to research with who may be most vulnerable.

IMPLICATIONS FOR RESEARCH

Contemporary mental health related research initiatives in low and middle income countries have exposed yet another dimension of the need for human rights protections and ethical standards. In low and middle income countries impacted by war, natural disaster and displacements, researchers have engaged in practices that need to be subject to human rights scrutiny. As regards children in research in general, the justification of non-therapeutic research (studies that do not purport direct benefit to participants) versus therapeutic research in children has been debated (Ramsay, 1976; McCormick, 1976). It has been argued that the use of children as research participants is never justified if they cannot derive benefit from participation (Ramsay, 1976) while others believe that as long as research involves no discernible risks, pain, or inconvenience, research is ethically permissible (McCormick, 1976). United States federal regulations (Protection of

The Convention on the Rights of the Child goes well beyond having implications for governments and should be considered in relation to all professional activities that impinge on the lives of children including clinical practice, research, participation and education.



Children must be treated “...without discrimination of any kind, irrespective of... race, colour, sex, language, religion...or other status.”

Convention: article 2.

Photo: Joe Healy and his family (Galt Museum & Archives)

Human Subjects) allow for non-therapeutic research that poses more than minimal risk with children, if:

1. Risk is a minor increase over minimal risk
2. Procedures are commensurate with general life experiences of participants
3. Findings are likely to yield knowledge of vital importance about the participant's condition; and
4. Parental permission and assent of the child are obtained.

History of medical and psychiatric ethical standards and guidelines

Ethical issues arise since youth are typically incorporated under the sub-heading “vulnerable populations.” Youth cannot care for or protect themselves independently and become more vulnerable when suffering from a mental illness. Some of these ethical issues around treatment, medication and research have been discussed in the field of child and adolescent psychiatry and psychology (Munir & Earls, 1992; Belitz & Bailey, 2009; Frank et al, 2003). Specific to psychiatric research, Roberts (1999) has developed a conceptual analysis of ethically sound psychiatric research protocols. Hoop et al. (2008) reviewed these topics in relation to research with youth. An extensive resource listing for psychiatric research ethics has been developed (Roberts et al, 1998). However, these guidelines are primarily for domestic trials, where researchers have authorizing institutional review boards, standards of care, and access to (often) multiple forms of “best treatment.”

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1977) allows studies that expose children to greater than minimal risk without intent to benefit participants when knowledge obtained is important to the future welfare of children. Sufficient evidence should be provided to show that: 1) research-induced pain or stress is not severe; 2)



“...a child who is seeking refugee status or who is...a refugee...[shall] receive appropriate protection and humanitarian assistance...”

Convention: article 22.

potential harms are reversible; 3) researchers are qualified; and 4) the setting is appropriate for the study (Fisher et al, 2007). However, when large asymmetries of power exist, it is unclear if the settings are appropriate to perform studies that do not provide benefit to participants.

Current medical and psychosocial guidelines for international research

The emergence of researchers from high-income countries conducting trials in low-income countries, particularly related to HIV/AIDS, challenged the Helsinki Declaration's framework for work in developing countries (Zion et al, 2002). In 1993, the *International Ethical Guidelines for Biomedical Research Involving Human Subjects* was produced to describe how the Declaration could be effectively applied to developing countries (Council of Medical Organizations of Medical Sciences, 1993). The Emanuel framework, though not specific to youth, addresses medical ethical issues that arise when performing research in low-resource countries (Emanuel et al, 2000).

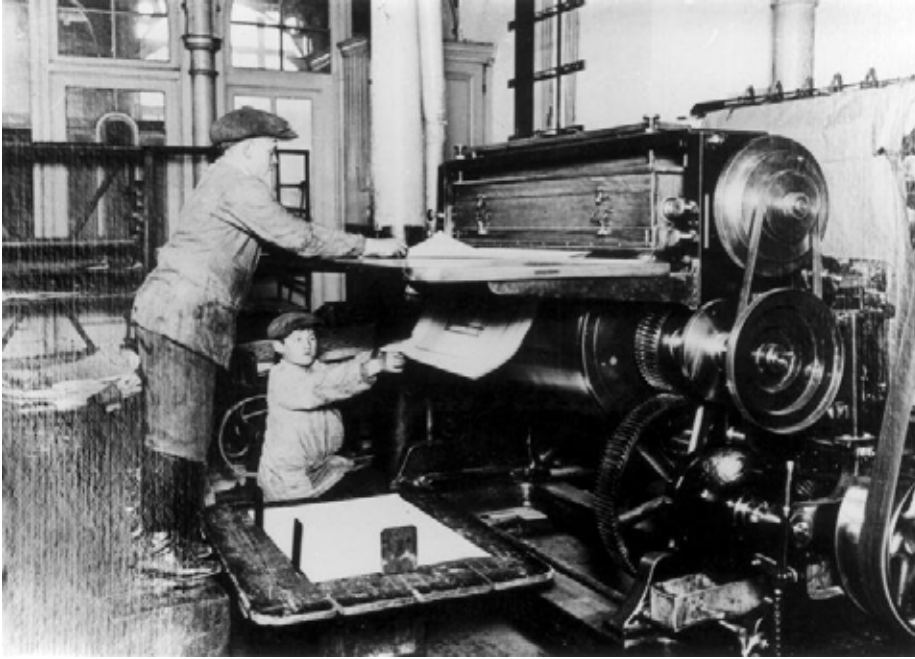
The psychosocial humanitarian field has ethical guidelines (Sphere Project, 2000; Morris et al, 2007; IASC, 2007; Allden et al, 2009). Others have suggested frameworks for research in low-resource, refugee, and international settings (Schenk & Williamson, 2005; Fisher et al, 2002; Leaning, 2001). These guidelines primarily aim at emergencies, conflicts or disasters, or focus on refugee youth in high-resource countries. Though the nature of child and adolescent psychiatry and allied professions demands knowledge of ethics (Munir & Earls, 1992), there is little training on ethics considering cultural or global contexts in the mental health field and, in particular, for those with disabilities.

Human rights of vulnerable populations

Vulnerable populations are special groups of people who lack the ability to protect their basic rights and liberties, making them open to exploitation. Children, in general, are such a population. War situations that create orphans who are not under the legal protection of an adult compound the issue of rights protection. War can also include specific populations (e.g., survivors of gender-based violence or child soldiers) that may be heavily stigmatized by the community and may be at potential harm from research if findings are released to the government, rebel forces, or the community.

Researchers engaged in therapeutic or non-therapeutic research should take ethical precautions and be sensitive to the needs of vulnerable groups. Children may not feel comfortable telling foreigners or adults about their experiences, especially in areas of political instability, where adults were involved in the conscription of children into armed forces. Revelations may place children at increased risk. Speaking at a child's developmental level, researchers should be clear from the start about their roles, what data will be collected, how it will be used, who will have access to it, and what the limits of confidentiality are. Special care should be taken to ensure that the collection, storage, and analysis of interviews or data are secured so participants can be reassured that their information (such as status as a former child soldier) will not be released to the government or rebel forces which could lead to further stigma and discrimination.

With limited access to resources for survival, families may be desperate to help their children and may view researchers as foreigners, whom they are used to seeing as humanitarian aid workers or as providers of food and material aid.



Children must be “protected from economic exploitation ... from [hazardous] work [and] all other forms of exploitation.”

Convention: articles 32 & 36.

Child labour in a printing company (kinderarbeid in drukkerij). Nationaal Archief/Spaarnestad Photo

Informed consent in low-income and post-conflict countries

Nontherapeutic research or the investigator’s intent to not benefit participants is *related* to informed consent. Informed consent includes examination about information, decisional capacity, and voluntary capacity (Roberts, 2002). Information should be relayed about the research process, timeline, methods to be used, and risks and benefits of participation in the study. Decisional capacity (Applebaum et al, 1982) is provided to researchers when individuals:

- Can communicate a voluntary non-coerced decision
- Can communicate an understanding of the risks and benefits of accepting or declining the treatment and potential outcomes of alternative treatments, or research
- Can appreciate the significance of the choice, and
- Are sufficiently cognitively intact to understand the consenting process and content.

Voluntarism capacity is equally important in war-affected countries, as being able to express ideas without coercion or threats to their true wishes (Roberts, 2002).

Informed consent should also take into account cultural variables, including education, concepts of youth, and respect for persons (Roberts, 2002). In areas with a high degree of illiteracy, the signing of a consent form may signal mistrust or dangerousness, especially in countries where the government has previously tricked people into relinquishing rights, as was the case in the former Soviet Union or Cambodia for example (de Jong, 2002; Ellis et al, 2007). In many low-resource countries, children enter the *labor* force as early as age five, and communities may have a different concept of who can provide consent for youth (Schenk & Williamson, 2005; Boyden, 2004). Researchers should have input from the community that is familiar with age, gender, social roles and expectations for child development and behavior (Schenk & Williamson, 2005). In a collective-society, an individual may consent to participate in research out of direct or indirect pressure from the

community, challenging autonomy (Ellis et al, 2007). The focus should be more on the achievement of true informed consent, rather than the final product of a signed document. This can be attained through research advance directives, which are discussions between researcher and subject, about the subject's motivations for joining the study, discussion about the likely outcomes of the study, and the protocol or procedure that will occur. Should subjects later enter a state where they lose ability to express preferences, the document will be able to direct next steps. Another way of solving this problem is by the use of verbal informed consent in the presence of a family member or friend (European Medicines Agency, 2009). Assent rather than consent is often used. This more passive approach to ensuring that the subject is informed is often easier to obtain in more naturalistic settings but runs the risk of not truly ensuring an informed subject population.

Asymmetries of power and information

When researchers from high-income countries come to devastated and socio-economically severely disadvantaged communities to conduct mental health research, local people may be at high risk of being exploited, as a researcher's social status can impact on research participation (Boyden, 2004). With limited access to resources for survival, families may be desperate to help their children and may view researchers as *foreigners*, whom they are used to seeing as humanitarian aid workers or as providers of food and material aid. As such, they may interpret participation in a study to be linked to the provision of assistance. Some child psychiatry research protocols offer clinical monitoring, which may be a strong incentive for those in war-affected areas that do not have clinical care accessible (Hoop et al, 2008). Moreover, well-trained Western mental health researchers may try to adapt their models of healing to a population foreign to them, and local communities may not have the free agency to decline participation, discuss negative effects or the impact on their local beliefs and practices, may feel coerced, or may report what they think the professional wants to hear (Fisher et al, 2002; Allden et al, 2009; Ellis et al, 2007). The asymmetry may extend to the involvement of local clinicians and researchers who compromise their local identity and concern for their constituents to be part of a more prestigious and sometimes more lucrative enterprise.

There can be asymmetry in the prioritization of needs as well. Researchers and clinicians who are foreign to the local community may not have research priorities that are congruent with local ones, despite the best interests being in mind. Often, foreigners have control over how funding will be used, program development and planning, determining who will receive services, and who will ultimately be trained to provide those services. Local governments are dependent on donors to fund research on donor-determined needs. This dependence on external funding and hence external researchers, may exclude local academics or Ministries from the opportunity to engage in an ethical analysis about subject communities, projects, and implications.

Ethical challenges inherent in therapeutic research

The definition of *therapeutic* research in low-resource settings is challenging, as a mental health researcher's role in these settings can vacillate between being an investigator and a provider of care. Moreover, the field of mental health is underdeveloped in these countries, causing Western clinicians to import and

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adapt interventions to different cultural contexts. The roles of researchers and the identification of the most appropriate intervention will be discussed below.

The boundary between researcher and clinician

The primary intent of a clinician is to provide help; whereas the primary intent for a researcher is to answer a scientific question. Inherent in the work with vulnerable children is the more porous boundary between researcher and clinician. Often there are no mental health clinicians, and the researcher is the first person to ask potentially emotionally charged questions about a child's experience in war. Interviews themselves are interventions. The researcher may knowingly or unknowingly become a clinician. Though the goal of a researcher is neutral—to collect data—each contact with a child is potentially a clinical one. There is some evidence that sharing a common stance with clients is valuable (Lustig et al, 2004), but likewise certain interventions may be harmful (Morris et al, 2007; Goodman, 2004). Psychiatrists, specifically, face additional difficulties in the field, as physicians may be confused about the divide between being a provider versus using patients to answer research questions (Jesus & Michael, 2009).

Conducting research without ensuring that appropriate services are available to those researched is unethical (Allden et al, 2009). Providing narratives of recent traumas, particularly in conflict situations, can put people at risk for psychological harm when not supported (Goodman, 2004). Interviewees with mental disorders, prior trauma, and low social support may be at higher risk for emotional distress (Dyregov, 2004; Jorm et al, 2007). However, there may not be a formal mental health system in war-affected, low-resource countries, with few clinicians or institutions to refer them to (de Jong, 2011; World Health Organization, 2005), and even in high-income countries like the United States, there are regions where many have difficulty accessing mental health services (Wang et al, 2005). Though researchers may not have the skills or means to provide support or assistance, there should be an obligation to learn about and access such resources (where they exist) prior to commencing research, or to develop supports for those who may express distress in the course of the research.

Identification of the most appropriate intervention

The *Declaration of Helsinki* proposes the *best current intervention* for the active comparator in a clinical trial. There are multiple established mental health interventions the superiority of which is debatable, depending on expert opinion. Randomized trials evaluating a school-based intervention (including trauma-processing activities, cooperative play, and creative-expressive elements) for war-affected youth in low-income settings in Indonesia (Tol et al, 2010), Sri Lanka (Tol et al, 2011), Nepal (Jordans et al, 2010) and Palestinian territories (Khamis et al, 2004), found promising improvements on select outcome measures for specific sub-groups, and others with no main effects on specific outcomes (Tol et al, 2011). In Uganda, a randomized control trial of interpersonal group psychotherapy with war-affected and displaced adolescents found effects for depression with girls only, and no effects for anxiety symptoms, conduct problems or functional impairment (Bolton et al, 2007). A randomized control trial in Bosnia-Herzegovina found improvements in posttraumatic stress disorder (PTSD), depression, and maladaptive grief with children receiving school-based trauma and grief-focused group psychotherapy, and improvements in PTSD and depression, but not

maladaptive grief in a classroom-based psycho-educational and skills intervention (Layne et al, 2008). A review of the evidence for interventions described as Sphere standard mental and social health indicators “suggests that even effective interventions can be harmful if applied at the wrong time, or targeted at the wrong segment of the population” (Morris et al, 2007).

CONCLUSIONS

It is remarkable that in the modern era the rights of children with disabilities remain such a challenge. Maltreatment of children with disabilities must be considered a critical public health issue (Hibbard et al, 2007). Contrast the availability of resources for children with a host of medical illnesses to those available to children with disabilities. International agreements are in place to end the era of isolation, abuse and neglect. The challenge is to increase awareness of the current situation and to educate a broad range of individuals to exercise their rights. Incrementally increasing participation of people with disabilities will lead to a lowering of the barriers that now prevent full participation in society.

The ethical evaluation of non-therapeutic research for vulnerable and war-affected youth demands researchers and clinicians to be *sufficiently* cautious with their work with vulnerable populations who are living in contexts with inherent asymmetries of power. Obtaining true informed consent from caretakers and assent from children should be a minimum standard for non-therapeutic research. Those conducting therapeutic research also have ethical considerations with the porous boundary between researcher and clinician, and how to determine the most appropriate therapeutic intervention to study. The benefits to society of documenting the effects of stress, evaluating the need for and access to mental health and other services, and the effectiveness of services for war-affected youth, all of which have potential to help society in the future, should be weighed against the mental health risks of conducting research in these settings.

The Convention and the CRDP offer hope for a new era respectful of human rights in the conduct of society and in research to find evidence for appropriate care. “The inclusion of children with disabilities is a matter of social justice and an essential investment in the future of society. It is not based on charity or goodwill but is an integral element of the expression and realization of universal human rights.”

REFERENCES

- Allden K, Jones L, Weissbecker I et al. Mental health and psychosocial support in crisis and conflict: report of the mental health working group. *Prehospital Disaster Medicine*, 2009; 24:s217-227.
- Applebaum PL, Roth LH, Lidz C. The therapeutic misconception: informed consent in psychiatric research. *International Journal Law Psychiatry*, 1982; 5:319-29.
- Belfer ML. Child and adolescent mental disorders: the magnitude of the problem across the globe. *Journal of Child Psychology and Psychiatry*, 2008; 49: 226-236.
- Belitz J, Bailey RA. Clinical ethics for the treatment of children and adolescents: A guide for general psychiatrists. *Psychiatric Clinics of North America*, 2009; 32:243-257.
- Bolton P, Bass J, Betancourt T et al. Interventions for depression symptoms among adolescent survivors of war and displacement in northern Uganda: a randomized controlled trial. *Journal of the American Medical Association*, 2007; 298:519-527.
- Boyden J. Anthropology under fire; ethics, researchers and children in war. In: Berry JBJd (ed): *Children and Youth on the Front Line*. New York, Berghahn, 2004.
- Carlson M. Child rights and mental health. *Child Psychiatric Clinics of North America*, 2001; 10:825-839.
- Clark P, MacArthur J. Children with physical disability: Gaps in service provision, problems joining in. *Journal of Pediatrics and Child Health*, 2008; 44: 455-458.
- Council of Medical Organizations of Medical Sciences (CIOMS). *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva, CIOMS/ World Health Organization, 1993.
- Dhanda A, Narayan T. Mental health and human rights. *Lancet* 2007; 370:1197-1198.
- de Jong JVTM. *Trauma, War and Violence: Public Mental Health in Sociocultural Context*. New York, Plenum-Kluwer, 2002.
- Duarte CS, Rizzini I, Hoven CW et al. The evolution of child rights councils in Brazil. *International Journal of Child Rights*, 2007; 15: 269-282.
- Dyregov K. Bereaved parents' experience of research participation. *Social Science & Medicine*, 2004; 58:391-400.
- Ellis BH, Kia-Keating M, Yusef S et al. Ethical research in refugee communities and the use of community participatory methods. *Transcultural Psychiatry*, 2007; 44:459-481.
- Emanuel E, Wendler D, Grady C. What makes clinical research ethical? *Journal of the American Medical Association*, 2000; 283:2701-2711.
- European Medicines Agency. *ICH Topic: Guideline for Good Clinical Practice*.
- Fisher CB, Hoagwood K, Boyce C et al. Research ethics for mental health science involving ethnic minority children and youths. *American Psychologist*, 2002;57:1024-1040.
- Fisher C, Kornetsky S & Prentice E. Determining risk in pediatric research with no prospect of direct benefit: Time for a national consensus on the interpretation of federal regulations. *American Journal of Bioethics*, 2007; 7:5-10.
- Frank E, Novick DM, Kupfer D. Beyond the question of placebo controls: ethical issues in psychopharmacological drug studies. *Psychopharmacology (Berl)* 2003; 171:19-26.
- Groce NE. Disability in cross-cultural perspective: rethinking disability. *Lancet*, 1999; 354: 756-757.
- Groce NE, Paeglow C. *Violence against Disabled Children. UN Secretary General's Report on Violence against Children. Thematic Group on Violence against Disabled Children*, 2005.
- Goodman JH (2004). Coping with trauma and hardship among unaccompanied refugee youths from Sudan. *Qualitative Health Research*, 2004;14:1117-1196.
- Hibbard RA, Desch LW & the Committee on Child Abuse and Neglect and the Council on Children with Disabilities. Maltreatment of children with disabilities. *Pediatrics*, 2007;119:1018-1025.
- Hoop JA, Smyth AC, Roberts LW. Ethical issues in psychiatric research on children and adolescents. *Child Adolescent Psychiatry Clinics of North America*, 2008; 17:127-148.
- Human Rights Watch. *Easy Targets: Violence against Children Worldwide*. New York: Human Rights Watch, 2001.
- Inter-Agency Standing Committee (IASC). *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings*. Geneva: IASC, 2007.
- Jesus JE, Michael GE. Ethical considerations of research in disaster-stricken populations. *Prehospital Disaster Medicine*, 2009; 24: 109-114.
- Jordans MJD, Komproe IH, Tol WA et al. Evaluation of a classroom-based psychosocial intervention in conflict-affected Nepal: a cluster randomized controlled trial. *Journal of Child Psychology & Psychiatry*, 2010; 51:818-826.
- Jorm A, Kelly C, Morgan A. Participant distress in psychiatric research: a systematic review. *Psychological Medicine*, 2007; 37:917-926.
- Khamis V, Macy R, Coignez V. *The Impact of the Classroom/Community/Camp-based Intervention (CBI) Program on Palestinian Children*. Save the Children US, 2004.

- Layne CM, Saltzman WR, Poppleton L et al. Effectiveness of a school-based group psychotherapy program for war-exposed adolescents: a randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry*, 2008; 47:1048-1062.
- Leaning J. Ethics of research in refugee populations. *Lancet*, 2001; 357:1432-1433.
- Lustig S, Weine S, Saxe G et al. Testimonial psychotherapy for adolescent refugees: a case series. *Transcultural Psychiatry*, 2004; 41:31-35.
- McCormick, RA. Experimentation in children: sharing sociality. *Hastings Center Report*, 1976; 6:41-46.
- Morris J, Van Ommeren M, Belfer M et al. Children and the Sphere standard on mental and social aspects of health. *Disasters*, 2007; 31:71-90.
- Munir K, Earls F. Ethical principles governing research in child and adolescent psychiatry. *Journal of the American Academy of Child & Adolescent Psychiatry*, 1992; 31:408-414.
- National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. *Report and Recommendations: Research Involving Children*. Washington, DC: US Government Printing Office, 1979.
- Pais MS, Bissell S. Overview and implementation of the UN Convention on the Rights of the Child. *Lancet*, 2006; 367, 689-690.
- Protection of Human Subjects*, 45 C.F.R. [section] 46.408.
- Ramsay, P. The enforcement of morals: nontherapeutic research on children. *Hastings Center Report*, 1976; 6:21-30.
- Rizzini I, Barker G, Cassaniga N. *From Street Children to All Children: Improving the Opportunities of Low-Income Urban Children and Youth in Brazil*. Cambridge: Cambridge University Press, 2002.
- Roberts LW. Evidence-based ethics and informed consent in mental illness research. *Archives of General Psychiatry*, 1999; 57:540-542.
- Roberts LA. Informed consent and the capacity for voluntarism. *American Journal of Psychiatry*, 2002; 159:705-12.
- Roberts LW, Solomon Z, Roberts B et al (1998). Ethics in psychiatric research: resources for faculty development and resident education. *Academic Psychiatry*, 1998; 22:1-20.
- Schenk K, Williamson J. *Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guideline and Resources*. Washington, DC, Population Council, 2005
- Slee PT. *Child, Adolescent and Family Development*. Cambridge University Press, Cambridge, 2002.
- Sphere Project. *Humanitarian Charter and Minimum Standards in Disaster Response*. Oxford, Oxfam, 2000.
- Stewart-Brown S. Research in relation to equity: Extending the agenda. *Pediatrics*, 2003; 112:763-765.
- Tol WA, Komproe IH, Jordans MJD et al. Mediators and moderators of a psychosocial intervention for children affected by political violence. *Journal of Consulting Clinical Psychology*, 2010; 78:818-828.
- Tol WA, Komproe IH, Jordans M et al (2011). School-based mental health intervention for children affected by war in Sri Lanka: a cluster randomized trial. Submitted for publication.
- Wang P, Lane M, Olfson M et al. Twelve-month use of mental health services in the United States. *Archives of General Psychiatry*, 2005; 62:629-640.
- Waterston T, Goldhagen J. Why children's rights are central to international child health. *Archives Diseases of Children*, 2008; 92: 176-180.
- World Health Organization. *Child and adolescent Atlas: Resources for Child and Adolescent Mental Health*. World Health Organization, Geneva, Switzerland, 2005.
- World Health Organization. *Atlas: Child and Adolescent Mental Health Resources. Global Concerns, Implications for the Future 2005*.
- Zion D, Gillam L, Loff B. Declaration of Helsinki, CIOMS and the ethics of research on vulnerable populations. *Nature America*, 2000; 6: 615-617.