Editorial

The UN Convention for the Rights of Persons with Disabilities is eliciting a lot of interest in the mental health sector. Carers' interest versus users' interest tops the list of cutting-edge controversies with respect to this Convention. Other issues being widely debated, raising controversies, relate to (1) full legal capacity for persons with a psycho-social disability and (2) demands against forced treatment. This issue of *aaina* carries an information update on the UN Convention.
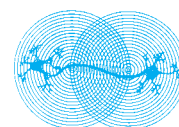
A carer's viewpoint on advocacy issues in mental health is being presented here. As a willing participant in a difficult conversation, *aaina* also brings the user perspective on full legal capacity. *Aaina* wishes to present more of this discussion in the forthcoming issues, so do write.

The spread of carers' groups in India and their push on the mental health sector was evident in a psychiatric meeting organized in Chennai, as the 6th Biennial Conference, by the World Federation for Schizophrenia and Allied Disorders, between 2-4th November, 2004. The event was hosted by *Aasha*, a carer's group from Chennai. Over 150 people participated, both from India as well as elsewhere. Equally evident in this event was the influence of bio-medicine and the pharmaceuticals. The event was funded by *Eli Lilly*, (makers of popular brands of anti-depressants), *Novartis* and *Pfizer*, all of them being MNCs in psycho-pharma. The event was opened by the President of the Indian Psychiatric Society. A useful directory of the carers' organizations gathered there was brought out, along with a comprehensive book of abstracts.

Another meeting concerning the rights of homeless persons with a psycho-social disability was organized by *The Banyan* in Chennai. You will find a brief report of their manifesto in this issue of *aaina*.

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aaina

a mental health advocacy newsletter

Aaina is a mental health advocacy newsletter. Advocacy demands critical, creative and transformative engagement with the state, policy makers, professionals, law, family and society at large.

Aaina is an opinion-making and opinion-leading newsletter, with a consistent message of user empowerment, good practice, policy, legal and social reform in the mental health care sector in India.

Aaina covers issues in community mental health, the role of NGOs in mental health, self-help and healing, the use of non-medical alternatives in mental health, human rights issues in mental health, institutional reform, ethical dilemmas, policy discussions, and the mental health needs of special groups (young people, women, the poor, sexual minorities, persons with a disability, etc.).

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Aaina covers themes related to disability caused by psychiatric drug use, and long term institutionalization. It has a great interest in how much money pharma companies are making by pushing hazardous drugs onto poorly informed communities.

Aaina provides a forum for users to express their problems and dialogues with the mental health service system, and their demands for change. It also addresses issues of social living for persons with a psychiatric disability, stigma, discrimination and deprivation of the right to life, especially of the poor and the homeless.

Aaina is circulated free to people concerned about these topics. It reaches out to over 300 people and organizations, and also to various policy makers and human rights watchdog agencies.

If you are interested in writing for *aaina*, or in receiving print copies, write to us at: *aaina@camhindia.org* You may also contact the editors at*: baputrust@rediffmail.com* or *satish.sadhana@vsnl.com* If you wish to make a donation to *aaina*, please make a DD or a cheque in favour of "*Bapu Trust for Research on Mind & Discourse, Pune*" and post it to our mailing address.

The UN Convention on Rights of Persons with Disabilities: An Information Update

- Prof. Amita Dhanda, *Faculty of Law, NALSAR, Hyderabad.*

Binding Obligations in International Law

A Convention or treaty is a binding legal obligation in International Law. The treaty or Convention has special binding quality because the obligations specified in it are those which States Parties have voluntarily entered into after a process of negotiation. The volition of the States enters into every stage of the process from negotiating to signing to ratifying. Even as State sovereignty is constantly asserted in the formulation of a Convention it would be important to appreciate that this freedom is relative. States are at different junctures subject to pulls and pressures from both the international community and their own citizenry. It is important to note that these pressures sometimes pull in the same direction and sometimes in opposite directions. It becomes thus a matter of speculation as to which pressure will win state assent and approval on the day. Along with Conventions there are softer instruments of international law such as General Assembly Declarations and Resolutions which are not binding on the States but which specify the direction that States are expected to adopt in relation to the issue on which the Declaration has been promulgated.

Factual Background

It is in background of this very basic understanding of international law that we need to appreciate the present international negotiations around the UN Convention on Disability Rights. Even though international law history makes mention of some unsuccessful efforts at attempting to frame a United Nations Convention on Disability, the UN law on disability has primarily been contained in some soft law instruments. Some of which are the UN Declaration on the Rights of the Disabled; the UN Declaration on the Rights of Persons with Mental Retardation and the United Nations Rules on the Equalization of Opportunities for Persons with Disabilities. In the present phase, a resolution for a Disability Convention was first introduced by Mexico in the World Conference Against Racism and when it received support,

Mexico pushed the resolution setting up the Ad Hoc Committee through the General Assembly. Consequent to this effort the UN General Assembly set up an Ad hoc Committee under the chairpersonship of the Ambassador of Ecuador to draft a Convention on the Rights of Persons with Disabilities. Mexico had also prepared a draft, which was presented publicly in connection with an inter-regional experts meeting in April 2002. It was also made available online for comment. A revised version was published before the first AHC meeting in July-August 2002. Besides the Mexico expert meeting, there were regional meetings held in Quito (Americas region), Bangkok (Asia Pacific) & Johannesburg (Africa). The Bangkok meetings held under the sponsorship of ESCAP were the most well developed and took place over a longer period of time, resulting in an actual text in October 2003. The Bangkok draft became the main source for the Chair's draft submitted to the Working Group. This draft provided the framework for discussion in the Working Group although the Group was free to depart from it in substance. The Group consisted of State parties, non governmental organizations and one National Human Rights Inistitution. The Working Group met for a two-week period in January 2004 and finalized its draft in that time . It is this working group Draft which is providing the foundational basis for negotiations between States parties.

The Working Group Draft , the suggestions by various States Parties as well as Disabled Persons Organizations can be electronically accessed on the United Nations website http://www.un.org/esa/socdev/enable/rights/adhoccom.htm

It is also important to note that there has been in the first instance various disability organizations, country and regional representatives of persons with disabilities started to participate as disparate groups. However increasingly through a process of continuous dialogue this disparate group of organizations has come to establish itself as a Disability Caucus on the Convention and is working hard

at speaking in one voice to the States. Details on the membership of the Caucus and some of its position papers can also be obtained from the above-mentioned UN website.

After having provided some general information on international law making and the working out of this in the realm of Disability I would in the rest of this note wish to focus attention on, one, some key conceptual controversies surrounding the Convention and two, specially zero in on those parts of the Convention which are of special interest to persons with psycho social disabilities.

Crucial Controversies

What should find inclusion in the Convention?

One issue which keeps resurfacing at the deliberations on the Convention in one form or the other revolves around what should find inclusion in the Convention? These questions arise because the Convention includes within its conspectus civil political rights such as : the right to life, liberty, freedom of expression or social economic rights like the right to work, health or rehabilitation or even special interests rights such as the rights of women or children. A number of States are at pains to point out that Conventions encompassing such like rights already exist and as these rights would also extend to persons with disabilities their reenactment in the Disability Convention was unnecessary. Whilst questions around the rights extending to special groups are still pending discussion the reiteration of the civil political rights has been conceded to on the reasoning that if these rights were in fact accessible to persons with disability there would be no need to deliberate on this Convention. Further these primary rights require inclusion in the Convention because they need to be tailored to the specific concerns of persons with disabilities. It should be noted that even as this reasoning is being conceded States are at pains to point out that the Convention is arising on the plank of non discrimination which means what is available to all other persons should also be available to persons with disabilities but not that rights which have not been conceded to the non disabled should be provided to persons with disabilities. Here the controversy very often is whether a reasonable accommodation provision is granting the same or more to persons with disabilities?

The Progressive Realization of Social- Economic Rights

It has been an accepted tenet of international law that whilst civil-political rights were immediately realizable social-economic rights had to be progressively realized. The fact that social -economic rights are resource driven is provided as the reason for the delayed implementation of these rights. One of the questions which is being vociferously argued in the present negotiations relates to the inclusion of an explicit provision which states that those social economic rights which do not require resources shall be immediately implemented. The States opposing such a provision are providing a multiplicity of reasons. Some of these reasons are that the idea of progressive realization implicitly acknowledges that those rights which do not require resources should be immediately enforced. An explicit mention is not needed. On being asked as to why which is implicit cannot be made explicit the reply is that if that were done persons with disabilities would be provided rights not available to others in the population.

What is meant by reasonable accommodation?

Evidently if discrimination of persons with disabilities is to be actively addressed it is necessary that their particular needs should be accommodated. And to ensure that this accommodation is not disproportionate and unlimited it is provided that such accommodation should not be unreasonable. Here in contrast to the reasoning which was put forth in the provision relating to progressive realization of social -economic rights a number of states are contending that the article itself should state that such accommodation should be made unless it results in disproportionate burden. The anxiety being expressed here is that such a qualifier would provide states with an escape route and negate one of the core concepts of disability rights.

How should the Convention mention families?

One of the key obligations of the States in the Convention relate to recognizing the participation and representational rights of persons with disabilities. A number of States underscoring the fact that several persons

with intellectual or multiple disabilities may be unable to represent themselves desire that this provision should not only make reference to persons with disabilities but to persons with disabilities and where appropriate their families. The Disability Caucus is contending that the participation should be of persons with disabilities and their representative organizations. Such a formulation it is contended allows for families and family organizations to be consulted where they are the representative organization and yet accords primacy to the aspirations of self advocacy. It allows for a merger of aspirational norms and pragmatic implementation.

Concerns of persons with psychosocial disabilities

Whilst the Convention is being negotiated on a global version of disability, it is still evident that some rights are of greater concern to people with some disabilities over others. In this section I recount the deliberations around the issue of legal capacity and forced interventions which have assumed special importance for persons with psychosocial disabilities because they more than any other persons with disability have been on the receiving end of incapacity labeling and compulsory civil commitment.

The working group has recommended that in article 9 (which deals with legal capacity) states parties should recognize persons with disabilities as individuals with rights before law equal to all other persons. They should also accept that persons with disabilities have full legal capacity on an equal basis with others. Where assistance is necessary to exercise legal capacity it should be proportional to the needs of a person. Such supported decision-making it is contended shall keep the wishes and aspirations of persons with disability in the forefront and in no case can the person providing support supplant the person with disability. The working group recommendation to the Committee took the stance that all persons could take decisions with support and substituted decision-making or guardianship was not required. In the reading of this recommendation in the May meeting of the Ad hoc Committee there was a proposal by Canada which was accorded support by other countries whereby a new paragraph was to be added to the article which allows for the appointment of substitute decision-makers or guardians for those persons with disabilities who are unable to take decisions even with support. These guardians are to be appointed after the observance of fair procedure safeguards which is usually understood to mean a court, hearing , representation by a lawyer etc.

The ground of controversy here is once the provision is included its applicability shall be tested against all persons with psychosocial disability. The very stereotype of incapacity which the Convention is intended to challenge shall be reinforced by the Convention. Hence the Disability Caucus and some states are contending that an effort should be made to see whether the functions of guardianship can be fulfilled through supported decision making and legal devices such as advance directives and powers of attorney. In mooting supported decision-making the disability caucus is making a distinction between the need to provide support to those who need it and allowing people the dignity of risk.

Guardianship is problematic as it in the name of providing the first also takes away the second.

The other issue of concern is how should the Convention deal with forced interventions? The Disability Caucus takes the view that a Disability Rights Convention should necessarily endorse the position of persons with disability that compulsory treatment was a contradiction in terms. And if it was not possible to unequivocally take this position then it was better that the Convention did not deal with the issue. It is further being asked is not the compulsory commitment of persons with disability because they are a danger to self or others discrimination? No other risk behaviour it is pointed out invites such like treatment. The Disability Caucus is therefore contending that behaviour dangerous to others should be dealt with under the criminal law and dangerous to self conduct should be prevented only if the State is planning to intervene in relation all risky behaviour.

Conclusion

The above note is aimed to provide an information update on the deliberations around the Convention and the discussions which transpired in the recently concluded meeting of the Ad hoc Committee from 23rd August to 3rd September 2004. As we ponder on the pros and cons

of various proposals it would be appropriate to remember that an international Convention in contrast to a domestic law and policy is aimed to be futuristic in its purport. It is made for not just for the near but also the distant future. Hence it should be providing direction setting principles. And the principles which we accept should be those which whilst acknowledging the limitations of the present do not stranglehold the future.

Prof. Amita Dhanda, a steadfast advocate for the rights of persons with psycho-social disabilities, has been a part of the UN Ad Hoc Committee meetings, as a part of the World Network of Users and Survivors of Psychiatry. For more details, and a continuing dialogue on the Convention, please contact:

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Institution
By Cynthia L. Damiano

Inside

Nothing grows deprived of

Sunny skies

In time

Unheard, with no opportunity

To bloom with grace

Instead the buds wither

On stems of

Neglect

(Source: Madness Network, Fall 1984, Vol 7, No 4)

The psychology of adolescence with sketches of guidance format

- Prof. (Dr.) Nilanjana Sanyal

- Miss Nilanjana Banerjee

ADOLESCENCE………

The key word brings as a hallmark to our general mental canvas of the profile of an "adult" in the making, with a health full of vitality, vigour, energetic, enthusiastic, colourful dynamic youth vibrating with spasms of life in possible positive directions. It is the time when individual talent begins to manifest itself in academic as well as in cultural dimensions. Negative profiles in the context is no rarity. Yet they should be considered as deviations.

Definition

Adolescence can be defined as a multi-dimensional developmental period, having distinctive behavioural ornaments here and there.

The existing scenario

A transitional life stage between childhood and adulthood is now evident in most of the societies of the world with their associated culture, specific patterns and practices. The new form of adolescence now taking hold across societies, however, are distinguished by a common set of historically recent elements associated with globalization that create a longer, more distinct transitional period [Schlegel and Barry(1991)]. These include longer schooling, earlier puberty, later marriage and for many youth, urbanization particularly, and greater separation from the world of adults. The pathways to adulthood— these adolescences—take different forms in different social, cultural and economic settings (Caldwell, Caldwell, Caldwell and Pieris, 1998; Larson,2002). In many societies, for example, this period does not involve the task of psychic separation from parents or carry the connotations of emotional turmoil with adolescents in the West (Dasen, 2000).

Adolescence in all parts of the world has been in in-flux of energy despite the changing socio-cultural fabric of current day societies due to globalization, urbanization, nuclear family and telecommunication revolution.

The basic process of adolescent development involves changing relations between the individual and the multiple levels of the context within which the young person is embedded. Variations in the substance and timing of these relations promote diversity in adolescence and represents sources of risk or protective factors across this life period.

Role of parents and peers during adolescence

For adolescents, this period is a dramatic challenge, one requiring adjustment to changes in the self, in the family and in the peer group. For both adolescents and their parents, adolescence is a time of excitement and of anxiety, of happiness and of troubles, of discovery and of bewilderment and of breaks with the past and of links with the future. If parents are aware of the path their child's development is supposed to take, they can be major supports during this period. They can also spot potential problems that need to be brought to the attention of correction and modification.

In this crucial phase of multi dimensional changes, peer relations play a significant role. (Bukowski, Hoza and Boivin, 1994). As children move into early adolescence, involvement with one's peers and attraction of peer identification increases. As pre-adolescents experience rapid physical, emotional and social changes, they begin to question adult standards and the need for parental guidance. They find it reassuring to turn to advice to friends who understand and sympathize—friends who are in the same position themselves (Laursen, 2001). Yet the word "peer pressure" comes with all the negative connotations of luring the adolescents into learning dangerous and destructive behaviour by discarding the parental values. But, on the other hand, peer pressure has enormous positivity in supplying emotional and moral support in the lives of the adolescents. It keeps youth participating in sports, religious activities and community welfare programmes even when they are not always the

leaders. The peer group is a source of affection, sympathy and understanding, a place for experimentation, and a supportive ambience for achieving two primary developmental tasks of adolescence: identity and autonomy.

DEVELOPMENT DURING ADOLESCENCE

Adolescents grow and develop in more "ways" and more "quickly" than people in any other age group. This "rapid" rate of change combined with changes occurring in all systems at once can produce problems and at best can be a difficult experience for the adolescent. Adolescents change in three ways—physically, cognitively and psycho-socially and no single influence acts either alone or as the prime mover of change.

Developmental path seems to be simpler if changes in all these three systems occurred simultaneously. The asynchrony among these can result in problems and developmental pathologies. In the context of "psychic development" of adolescents, the cognitive as well as the psychosocial growth needs further clarifications and probing.

Cognitive development:

During adolescence, with the development of body in size, strength and reproductive abilities, the mind becomes capable of more abstract thinking, future orientation and ethical convictions.

The key features of this kind of formal thought is the ability to:

➢ Generate abstractions

➢ Generate hypothesis

➢ Consider contrary-to-fact situations

➢ Generate all possibilities from a specific situation

➢ Approach a problem in a systematic fashion

➢ Use "combinatory logic"(the ability to combine ideas to derive a conclusion)

These developments in thinking needs nurturing in order to grow further, since developing a realistic self-image is dependent on effective cognitive development.

Psychosocial development

This refers to the teenager's growing ability to relate realistically to other people, to learn to become a mature partner in an intimate relationship and to see oneself realistically. This type of development may never actually end, but a good deal of it should be accomplished before a person can be considered an adult. There are four tasks involved in becoming psycho-socially developed. They are:

➢ The ability to separate effectively from the parents both emotionally and intellectually while still retaining the bonds of the family

➢ The ability to choose a realistically vocational goal

➢ Developing a mature sexuality

➢ Developing a realistic and positive self-image

For this type of development, adolescence is divided into three stages:

- Early adolescence: from about 10-13 years old

- Middle adolescence: from 14-17 years old

- Late adolescence: from 18-21 or 22 years age

These age changes are not absolute, but they work as a good general guide to pinpoint the different patterns of psychosocial changes at different adolescent stages, like early adolescents desire to become independent in a totally non-rational manner whereas late adolescents acknowledge that parents may not be infalliable, but can be their best friends.

The major psychosocial features of adolescence tend to be:

➢ Intimacy-forming close socio-emotional relationships with others

➢ Autonomy-establishing a healthy sense of independence

➢ Identity- becoming a successful and competent member of society

In the task of such attainments, parental control tend to fall away rapidly and for today's adolescents, it is true

that they search out sources of information other than parents that give them an independent status as opposed to earlier dependent one. Here the mass media and internet provide attractive alternatives. Adolescents are found to resonate with media content depending on the developmental task at hand. In Indian context specifically, adolescents' independence is not as much in terms of monetary aspects as it is in the decisions regarding personal appearance, habits and manners, vocational, social, recreational and educational choices of adolescents.

In an overall stance, across cultures and classes, the select 'psychic' features of adolescents tend to be:

➢ Time of seeking status as individual

➢ To be within the emotional embraces of peer group relations, attaining status and recognition by the age mates

➢ Attainment of physical maturity

➢ Time of intellectual expansion and of academic experience

➢ A time of development and of evaluation of values. It is a time of conflict between youthful idealism and reality

Sexuality also is a strong component of psychosocial development during adolescence (Browning et al.1999). It involves a person's sense of self as a man or woman. It is the ability to enter into and maintain an intimate relationship with the significant other, and the ability to relate to other people in general (Kinsman, Romer, Furstenberg and Schwartz, 1998). It is composed of the following factors:

➢ Biological: ones genetic make-up and the way it is expressed (one's appearance)

➢ Familial: the role modeling provided by and the behaviours demonstrated by the closest adults to the adolescents, usually the parents

➢ Cultural: the roles assigned to men and women by the adolescent's culture and the ways in which men and women are supposed to interact

➢ Societal: the mix of cultural norms that make up the society

Adolescent sexuality is expressed differently at each stage of development during adolescence:

1. The early adolescent is basically working on hormones and the models provided by parents and other adults close to the adolescent. These factors, combined with a new self awareness that produces intense embarrassment, makes up sexuality at this phase. Adolescents will have romantic fantasies about ideal partners, but they will usually remain fantasies.

2. Middle adolescents have become surer of themselves. Their bodies are settling down, and they are more comfortable with mixed-sex peer groups. They still have fantasies of ideal partners, but they can try out some behaviours (for e.g. in parties) that cause parental anxiety.

3. Late adolescents will have reached the point at which they can begin to enter into relationships giving to their partner as much as they receive, the hallmark of an adult relationship. Conflicts about sexual preference are being worked out, and thoughts about more permanent relationships occur.

Risk behaviour during adolescence

Because adolescence, more than any other stage in the life span, is likely to involve experimentation and exploration, it is not surprising that we observe the emergence of risk behaviours (Steinberg, 2002). Two trends characterize the nature of risk behaviours in adolescence. First, some risk behaviour is normative. For e.g., a majority of adolescents will at least experiment with smoking. Second, risk behaviours increase in adolescence, although the developmental course that a particular behaviour follows (when it reaches its height) is unique to the specific behaviour (Achenbach, 1991). Delinquency, for instance, rises and falls in adolescence, but alchohol use and sexual intercourse may continue to increase in adulthood.

Across the diverse sets of individual and contextual factors that are associated with the actualization of risk behaviours in adolescence—that is teenage pregnancy and abortion, transmission of STDs due to unsafe sex, decline in school attention, performance and educational aspirations and substance abuse and delinquent behaviour- or with the prevention of these risk behaviours, respectively, there are six common characteristics that are involved in the occurrence of one or more of these risk behaviours (Cicchetti and Dawson, 2002). They are as follows:

- ➢ **Age:** the earlier the initiation of any of the risk behaviors of adolescence, the more likely it is that the youth will engage in the behaviour to a great extent and that he or she will suffer negative consequences.

- ➢ **Expectations for education and school grades:** Youth who do not expect to do well in school, and who do not actually do well, are at risk for the problem behaviours reviewed.

- ➢ **General behaviour:** Inappropriate behaviours and inadequate conduct (e.g. acting out, truancy and conduct disorders) are related to the appearance of risk behaviours.

- ➢ **Peer influences:** An individual's likelihood of engaging in problem behaviours is not just due to individual factors (such as early pubertal maturation) but due to contextual factors as well, for instance, having peers who engage in risk behaviours.

- ➢ **Parental influences:** Particular styles of parenting – that is authoritarian or permissive styles, as compared with an authoritative one, place a youth at risk for problem behaviours. In addition, if adolescents are not positively affectively tied to their parents, risk behaviours are also likely to occur.

- ➢ **Neighborhood influences:** The community context also plays a role in the development of risk behaviours. A neighbourhood characterized by poverty, or by urban, high-density living, is more involved in risk actualization.

Hence 'psychic' growth and development during adolescence flashes itself as multi-faceted process, involving every aspect of a young person's being. It is rapid and can be confusing and distressing.

Dealing with the Adolescents: Some Tips for Parents and Professionals

Each generation of young people and their families face new, and perhaps more challenging, circumstances. Parents are understandably troubled by the confrontational nature of some adolescent behaviour. They also worry about other actions that may threaten the safety of their child. Early intervention with young people who are troubled is crucial to reducing problems, or the resulting acting out behaviour might cause (Collins and Russell, 1991). The parents need to be alert and notice the following warning signs that their child shows when in trouble, indicating that they need help:

- ➢ Large amounts of time spent alone and isolation from family and friends

- ➢ Sudden changes in school performance

- ➢ Drastic mood swings or changes in behaviour

- ➢ Changes in the child's peer group or separation from long-time friends

- ➢ Lack of interest in hobbies or social and recreational activities

While there are no easy answers in parenting, the following strategies may help the parents to support their child during adolescence while reducing the risk of serious harm either to the child or another person (Baumrind, 1991):

- ➢ Educate yourself about adolescent development. Learn about the behaviours to expect, the effects of physical changes and ways to help your child deal with change and respect their need for privacy.

- ➢ Remember your own adolescence—your changing feelings, anger at authority, and fears and hopes and look at your adolescents behaviour in that context. Understand the adolescent's developmental urge to challenge the authority.

- Listen more than talk. Young people have spent at least a decade as listeners in most situations. During adolescence, they want and need the chance to share their feelings and ideas and to begin recasting family beliefs and traditions in the light of their changing identity.

- Teach your adolescent about the joys and troubles of life and ways to revel in the good times and cope with the bad. Teach practically how to deal with stress.

- Use positive reinforcement for positive behaviour whenever possible; it is far more effective than criticism or punishment for negative behaviour. Words that belittle can hurt your adolescent's self esteem. The most useful tools in raising young people are love, compassion, sensitivity, affection, praise, understanding and communication. Be flexible while making and reinforcing rules.

- Teach your adolescent that rights and responsibilities go hand in hand, and give your child increasing responsibility for his/her personal well being and that of the family.

- Help your adolescent move toward independence. Becoming attuned to your adolescent's attempt to operate independently will help you to support those efforts and provide proper guidance whenever they take any decision. Encourage your adolescent to set reasonable but challenging goals.

- Show interest in their school activities and encourage getting involved ingroup activities. Talk about choosing friends in school and having good relationships. Explore ways to help deal with peer pressure in school.

- Offer your child chances to become involved in the community. Their involvement in developing solutions to community problems can shift their focus from themselves and help them to develop skills and feel involved and empowered.

- Spend quality and quantity time with your adolescent and do things that are enjoyable.

- Accept that you have feelings too. You may feel fustrated, angry, discouraged or sad during difficult times with your adolescent. Model the ability to apologize when you feel that you let your emotions get the best of you. Your example will help your adolescent understand human frailty and ways of mending relationships strained by stress or disagreement.

In spite of the above efforts, the parents might fail to deal effectively with their adolescent and might have to seek professional help. The important points that a professional needs to keep in mind while dealing with an adolescent are:

- Find ways to help adolescents cope with anger and resolve conflicts without violence.

- Observe signs that he/she is feeling nervous, lonely or 'that' things are just not going right.

At the end, we must not forget that adolescents strive for independence and identity and to help them fulfill their dreams and desires we need to:

- We must locate the inner resources in their individuality.

- We must respect their specificities and differences from us.

- We must love them unconditionally.

- We must not personalise their odd behaviour to us.

- We must offer them opportunities of growth and needed corrections.

- We must try to portray us as level-best role models to them.

Given adequate support, guidance, firm limits and unconditional love, adolescents can make it through this turbulent time with minimal damage and with a vision of a positive future as a contributing adult.

To understand their 'psyche', we need to look back into our 'youth days' and keep a smile on our face thinking, 'they would also be the level-best role models for the next generation'.

References:

- Achenbach, T. M. (1991). Integrative guide for the 1991 CBCL/4-18, YSR, and TRF Profiles. Burlington: University of Vermont.

- Baumrind, D. (1991). Effective parenting during the early adolescent transition. In P.A.Cowan and M.Hetherington(Eds.), Family transitions (pp.111-163). Hillsdale, NJ;Erlbaum.

- Browning, J. R., Kessler, D., Hatfield, E., & Choo, P. (1999). Power, gender, and sexual behaviour. Journal of Sex Research, 36, 342-347.

- Bukowski,W.M., Hoza, B., & Boivin, M. (1994). Measuring friendship quality during pre and early adolescence: The development and psychometric properties of the friendship qualities scale. Journal of Social and Personal Relationship, 11, 471- 484.

- Caldwell, J. C; Caldwell, P.B.K and Pieris, I. (1998). The Construction of Adolescence In a changing World: Implications for Sexuality, Reproduction and Marriage. 'Studies in Family Planning', 29, 137-153

- Cicchetti, D., & Dawson, G. (2002). Editorial:Multiple levels of analysis. Development and Psychopathology, 14, 417- 420.

- Collins, W. A., & Russell, G. (1991). Mother-child and father child relationships in moddle childhood and adolescence: A developmental analysis. Developmental Review, 11, 99-136.

- Dasen, P.R. (2000). Rapid Social Change and the Turmoil of Adolescence: A Cross-Cultural Perspective. 'International Journal of Group Tensions', 29, 17-49.

- Kinsman, S. B., Romer, D., Furstenberg, F. F., & Schwartz, D. F. (1998). Early sexual initiation: The role of peer norms. Pediatrics, 102, 1185-1192.

- Laursen, B. (2001). A developmental meta-analysis of peer conflict resolution. Developmental Review, 21, 423-449.

- Schlegel, A. & Barry, H (1991). Adolescence: An Anthropological Inquiry. New York: Free Press.

- Steinberg, L. (2002). Clinical adolescent psychology: What it is, and what it needs to be. Journal of Consulting and Clinical psychology, 70, 124-128.

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National Workshop on
Mental Illness and Homelessness
25th-27th August, 2004

A brief report

Homeless people are considered the most vulnerable members of any society. The lack of secure housing, regular sources of income and therefore low levels of nutrition, no access to health care and education are highly prevalent amongst the homeless. Limited access to government facilities and entitlements as well as constant threats of eviction further aggravate already precarious living conditions. Mental illness, alcohol abuse and substance abuse are found to be 3 to 5 times as high among the homeless as compared to the general population. Medical care for homeless people with a mental illness is not available at the government sponsored primary health care level. The Mental Health Act (1987) has made provisions for the care and treatment, and rehabilitation, of the homeless mentally ill men and women. Despite these provisions, concerned authorities have consistently turned a blind eye towards these people. Care for the homeless mentally ill has become the sole responsibility of the NGOs.

Against this context, *The Banyan*, Chennai, had organized a 3 day National level workshop on "Mental illness and homelessness", supported by Sir Ratan Tata Trust. The objectives of the workshop were to bring together NGOs and government agencies to discuss the situation of the mentally ill homeless in various parts of the country, to share experiences, and to identify areas for action. 4 thematic issues were discussed by forming discussion groups:

1. Putting Mental Health on the Agenda of Government and NGOs

2. Promoting early identification of mental illness and community based access to care

3. Enhancing quality in care for the homeless mentally ill

4. Ensuring legal and economic support for the mentally ill

The full report of the working group recommendations can be downloaded from the Banyan website: www.thebanyan.org

Workshop Manifesto:

The workshop participants jointly identified the following 24 key areas for action and resolved that these will be the focus of their work:

1. Right to mental health as a basic right

2. Facilitate the access to mental health care to prevent homelessness due to mental illness, and remove all administrative bottlenecks

3. Mainstream the services for the homeless mentally ill persons in all the relevant programs in the local context

4. Promote partnership of Government, NGOs, professionals to address the needs and rights of the homeless mentally ill

5. Promote transparency and de-custodialisation in mental health institutions and all other care institutions

6. Reinvestigate the current status of the police as the first point of contact and explore alternatives

7. Social mobilization through inter-sectoral co-ordination including the media to de-stigmatise mental illness and promote awareness

8. Models (and services for making them accessible) should be ethically sound and legally permissible

9. Formulate a policy for involuntary admission and discharge with necessary checks and balances

10. Establish wholistic models of mental health care

11. Make available and publicise a databank of professionals and services

12. Create a multi-representative nodal agency at the state level to document and address issues pertaining to the mentally ill homeless

13. Recommend amending and updating the Mental Health Act's provisions of admissions, discharge, licensing, rehabilitation and the needs of the homeless mentally ill

14. Promote common minimum standards and accountability in care and intervention of the mentally ill

15. Delineate the common minimum components of rehabilitation to be followed

16. Augment, formulate and monitor funding for the homeless mentally ill

17. Include the issues of the mentally ill homeless in the National Mental Health Program and the DMHP

18. Institute a central helpline number to reach out to the needs of the mentally ill homeless

19. Provide legal services for the homeless mentally ill

20. Facilitate access to social security measures provided for disabled people including all schemes under the departments of Social Justice and Empowerment, Human Resource Development and Health

21. Recognize that the condition of homelessness contributes to mental illness

22. Conduct training to build on existing human resources in the field of mental health

23. Provide shelters for the homeless

24. Involve users and carers in policy and programme formulations regarding the homeless mentally ill

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All back issues of *aaina* can be freely downloaded from our website:

www.camhindia.org

WNUSP, the World Network of Users and Survivors of Psychiatry, has recently adopted the following note on "legal capacity". This Note, prepared for the WNUSP, by Dr. Amita Dhanda, spells out the position of this world coalition of psychiatric users and survivors, on the right to full legal capacity for persons with a psycho-social disability.

Capacity in law constructed by society:

The first thing to appreciate in relation to legal capacity is that it is socially constructed and is thus reflective of choices societies have made at different points of time. Historically capacity has been an attribute or a presumption that the law has conferred or denied from populations. A useful illustration of this process is provided by the legal management of the capacity of women. The negotiable content of the concept is again demonstrated by the Convention on the Rights of the Child acknowledging the evolving capacities of the child and explicitly incorporating the right to participation (Article 12). Therefore when we are asking for the legal disqualifications applicable against us (persons with psychosocial disability) to be lifted we are in a manner of speaking treading paths traversed by other excluded groups. We are saying that the allegation of incapacity that society makes in relation to some or all of us is false and we have a right to live like any other on our own terms.

Cognitive Capabilities Privileged in Legal Construction of Capacity

Whilst accepting the constructed nature of legal capacity (it is necessary to understand) that it is primarily constructed from a normative standard of cognitive capabilities. This privileging of cognitive capabilities is questionable as not all of us use cognitive capabilities to make our decisions. Should those of us who use an emotive or intuitive basis for reaching decisions be considered incapable? The law by according primacy to a certain way of being in the world seems to be manufacturing incapacity labels. If the presumption comes into being because of the way in which the law treats different kinds of intelligences then evidently a Disability Rights Convention needs to change this presumption and recognize these differences. This process would stand initiated if the Convention should unequivocally state that all persons with disabilities have legal capacity.

Legal Capacity not to do with Wisdom of Choices

One of the arguments put forth for substituted decision-making is that a number of persons do not have the wisdom to exercise legal capacity. But legal capacity is about the freedom to make choices and not the wisdom of those choices. There is an inherent freedom for all human beings to make the same or new mistakes and to learn or not learn from them. This liberty to learn from mistakes is at other than legal sites referred to as experimentation or even learning from trial and error. Humanity has progressed by allowing people the freedom to make mistakes. This may be because it has often been found that the blunder of today becomes the discovery of tomorrow. Whenever any people are not accorded the freedom to make their own errors they are in effect not being allowed to develop in accordance with their own genius and it is this discrimination and deprivation that needs to be addressed in relation to persons with psychosocial disability. Dignity of risk and the right not to be protected are inherent rights of all adults. A Convention which is being negotiated to return to persons with disability their full personhood has necessarily to interrogate all stereotypes because if it were to get entrapped by stereotypes it would not just reinforce a mistaken impression it would legitimize it.

Need to Distinguish between a Norm and its Implementation

It is next contended by the proponents of guardianship that supported decision-making cannot substitute for guardianship and even if it could such support is not available. These arguments it is submitted conflate the concerns of implementation into the adoption of norms. Should these constraints of implementation provide the basis for adoption of norms under the Convention especially when the norms adopted under the Convention will be the basis of all future discourse on rights of person with disabilities? A pragmatic approach for the implementation of norms is acceptable but a similar perspective towards the adoption of norms is questionable because this is letting the limitations of today confine the developments of tomorrow.

Substituted Decision Making will apply to all persons with psychosocial disability

A further argument by proponents of some form of substituted decision-making is that as a rule all persons with disability have legal capacity but there are a very small percentage of persons with severe disability for whom supported decision-making will not be sufficient and for whom guardianship will need to be provided. Proponents argue that these guardianship arrangements should be put in place subsequent to determination by a judicial body after due observance of fair procedure safeguards. They contend that this substituted decision-making will be the exception not the rule and would apply to a small percentage of cases.

The first consequence of accepting this argument will be that the rule of substituted decision-making will need to be incorporated in the Convention. Now the rule according to its proponents has been incorporated only for a very small percentage of persons with psychosocial disability. It therefore becomes necessary to ask by what procedure this small percentage of persons will be identified. Evidently this will be done from case to case. This process of identification will render the capacity of all persons with psychosocial disability open to question.

This would give rise to a situation where for questionable advantages to a small group of persons all persons with psychosocial disability shall be disadvantaged. The contention of questionable advantage is being made because studies evaluating the functioning of guardianship have found abuse isn't in fact prevented with guardianship, it is facilitated. Further these arrangements once made cause the guardian to take all decisions on behalf of and without consultation with the ward. This ouster makes for the civil death of the persons subjected to guardianship.

Supported Decision Making the Sole Model

In the circumstances it may be worthwhile to ask if the paradigm of supported decision-making would be a preferable option for all persons with disability as it would keep us at the centre of all decisions affecting us. It would interrogate the cognitive privileging existing in present laws and yet allow persons with disabilities along with others needing help to seek assistance in those tasks which require higher reliance on cognitive capabilities.

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Carers' Advocacy in Mental Health- AMEND / ACMI

- Nirmala Srinivasan and Laila Ollapally

There has been a continuing discussion among the "consumers" of mental health services (including both carers as well as the end users of psychiatric services), about human rights issues. The carers groups are forming politically informed groups all over India. AMEND has been one of the earliest initiatives of carers' mobilization. AMEND here clarifies the concept of "advocacy" in the mental health area. How the carers' political platform is different from the medical professionals' on the one hand, and from the end users, on the other hand, is evident from this article. Particularly worthy of critical discussion is the suggestion that availability of more psychiatrists, and more psychiatric drugs, is a "human rights" issue in mental health policy making.

Introduction

Advocacy has become a buzz word in the development sector among human rights activists NGOs, and other social entrepreneurs. The Persons with Disability Act 1995 , GOI, has enhanced scope for such initiatives in disability sector too especially for Mental Illness by recognizing it as a disability on par with other disabilities. Advocacy sounds an intimidating term to many but the idea is more frightening than the activity. In simple terms, it means actively supporting a cause and successfully getting others support as well. However, this definition is full of ambiguity and can be even be misleading. For example, we wonder whether a school run for mentally retarded children can be called an advocacy initiative at all just because it serves the cause of a few affected persons and enjoys the patronage of local community? This debate is ideological and hence replete with political overtones.

To justify claims to advocacy action is to make our value positions clear as social activists and change agents. Advocacy initiatives are not projects but movements that influences political climate, public perceptions, policy decision and budget allocations. *They are architectonic models of social change that impacts the entire target population and not just a few individuals here and there.* In order to drive home the essential features of advocacy oriented activities, this writer has drawn illustrations and examples from the disability sector pertaining to the field of psychiatric disability caused by mental illness.

A fundamental issue about advocacy is the identification of stakeholders. In the case of the persons suffering from mental illness, the families and the affected persons (reliable sources put it at 100 million and 50 million respectively in India) become primary stakeholders Unfortunately, most policy decisions are made by government officials and mental health professionals on behalf of the largest stakeholders but without their participation! Unfortunately, this has led to enormous social, legal and political anomalies besides violation of basic human rights of the affected persons and their family care givers. Family care being an integral part of the mental health care in India, to de-link the needs of family care from the rights of the patients results in insensitive, inadequate and unimaginative delivery of mental health services besides increasing the scope for commercialization.

The moot point however is that only 5% of India's 40 to 50 million receive treatment; since early treatment is early "recovery", *ACMI*'s primary concern was to ensure that medicines and doctors are available and affordable. But before we touch upon the praxis of advocacy initiatives by *ACMI,* let us understand the concept of advocacy.

What is advocacy?

Defining advocacy is like seven blind men finding the elephant's tail on account of the social / professional background of volunteers and agents. The ideological differences percolate down to the choice of advocacy agenda and action. For the service providers like

psychiatric counselors, advocacy can range anywhere from professional responsibility of providing therapy to the other extreme of whipping up an anti-therapy lobby because it is an "invasion" of mind. Even within the therapeutic paradigm, choice can range between religious counseling, supportive therapy, cognitive or transactional/ regression therapy. All these approaches that constitute rehabilitation package for the affected persons cannot be justified as efforts in advocacy because the *access to therapeutic services is limited to a few individuals and does not guarantee it as a right to access therapy as part of right to treatment. In most cases, it is a service that is bought, because as of now, free therapy services is restricted to only a few hospitals.*

Therefore, ideological interpretations provide **the core character for defining** advocacy. It is the only litmus test to end the prevailing semantic confusion over what is advocacy.

Similarly,**"*Right to Patient Information*"** or **"*Right to family therapy*"** can be defined as advocacy activities as against **"*Accees to Patient Information*"** and **"*Access to family therapy*"** which are only basic services. In other words, advocacy initiatives are to be clearly distinguished from a regular mental health and psychiatric service by examining the scope of a particular service as a **Citizenship (Political) right of the mentally ill** under the Constitution of that country. So availability of treatment choices (especially as commercial ventures) are not advocacy *per se; but the Right to treatment is so.* Similarly, opening rehabilitation homes are not advocacy initiatives; but by defining the right to rehabilitation as a legal right of the mentally ill, we are ensuring that the entire population of affected persons is brought under the ambience of social justice and rule of law.

Most importantly, by ensuring various services as rights, we are also broadening the base of service to those who cannot afford to access the same. For example, for many mentally ill persons in our country, rehabilitation homes are a luxury that they can ill afford. However, by defining it legally as part of their right to health care, the mental health policy gets legally framed to translate human rights into the body of legislation. Unfortunately the legislations for mentally affected individuals in India woefully lack radical human rights edge. Hence besides,

mental health for all, *ACMI* 's concern is equally influenced by the human rights dimensions of justice and dignity.

Similarly, small and big campaigns are going on by various lobbies for the mentally ill in this country. Unfortunately, we are yet to crystallize as a single lobby of consumer-caregiver identity. However, the self help group AMEND has successfully campaigned for issue of identity cards to the mentally ill in Karnataka on par with other disabled. Following in the footsteps of AMEND is ACMI, Action for Mental Illness which has taken off into legal advocacy beyond political campaigns.

An excellent illustration of professional advocacy from the Indian Psychiatry Society is the designing of IDEAS (Indian Disability Evaluation and Assessment System) for measurement of disability in psychiatric patients for issuing certificates to obtain identity cards under the Persons With Disability Act 1995. Among its many benefits are IT exemption exclusively for the mentally ill- yet another feather in the cap of AMEND that has enabled thousands of caregivers and consumers who file taxes benefits! However, it is a different story altogether that many parents are not aware of this new development.

Effective advocacy initiatives encompass political, legal , social and informational inputs. Currently, ACMI is into all the four levels of advocacy action and campaign.

Types of Advocacy

1. Political Advocacy involving interventions at policy making level by influencing the decision making bodies of civil society and if possible budget allocations, policy changes and amendments to existing law. ACMI's participation in various government bodies especially in the Plan of Action For Mental health Care sub-committee of the provincial government of Karnataka in India, marked a major step in the distribution of decision making power between officials and care givers to decide on the budget for the first phase of Crisis Plan for mental health program in the state of in Karnataka.

2. Legal Advocacy initiating relevant Court litigations, directions and orders. ACMI's involvement in an ongoing litigation in the High Court of the state of

Karnataka brought to focus the urgent issues such as the non-availability of psychiatrists in rural areas. Lack of psychiatric drugs, absence of minimum standards in hospitals and nursing home besides vocational and rehabilitational facilities for the poor in villages were other issues. Until then, the Free Legal Aid Board being the party was not assisted by the voice of the actual consumers. ACMI through its active care giver representation in the person of Nirmala Srinivasan, brought the Family care and Consumer perspective to the Court that were never heard of before.

Similarly, ACMI has intervened in the Supreme Court in an ongoing litigation by Psychaitrists to bring to the attention of the Court, the pain and suffering of the actual consumers.

3. Social Advocacy by educating and empowering family members or caregivers, family associations; even initiating grass root mobilization of family members as potential self help lobbies and pressure groups. Current social advocacy projects of ACMI known as KSHEMA is Family to family Education and Empowerment projects carried out in the community and in the premier national Mental health Institute called NIMHANS in Bangalore. The project is unique in the sense that all KSHEMA guides are AMEND family members trained by ACMI to carry out this unique grass root mission.

4. Informational advocacy conventionally entails media publicity, publication of literature, lecture campaigns in schools and colleges, government officials including police and stigma busters etc. In the case of ACMI, our website www.acmiindia.org is the first of its kind aimed at empowering the Family care givers of the mentally ill persons in India because we believe *an empowered family is an educated family; and an educated family is an enlightened family"*.

We are proposing a series of street plays besides documentary films.

Conclusion

An advocacy lobbyist in the true sense of the term, must campaign from a political platform of Human Rights than Services. Advocacy is therefore a political movement with a strong ideological character that defines the means and the end. If the end is disability rights and justice, the means have to be political and legal activism. An advocacy lobby is a political lobby.

The road to advocacy can take many forms. It need not necessarily start with an annual planner in front; in most cases, it is born out of personal *angst*, sense of personal deprivation and injustice. But political support and educating policy makers is an integral part of a comprehensive advocacy campaign. Educating policy makers in advocacy issues need a tremendous amount of groundwork especially in figures, statistics and numbers though the initial impetus may be personal and hence emotional. Above all, it needs the singular commitment of an advocate who on many occasions end up launching a lonely crusade.

Another critical factor is funding the advocacy campaign. The VCs and corporate funding agents still want to go by the book replicability, sustainability and ROI concerns! Investors especially in India are not yet ready for the adventurous game of funding advocacy campaigns that does not yield itself to input-output analysis. Identifying a funding agency is the biggest challenge of advocacy initiatives. The Corporate Social Responsibility models have to design novel and innovative performance measurement models to evaluate advocacy projects. Of greater interest is the underlying political ideology of the funding agency and the activists. Very rarely do we find them in synchronicity with each other!

Challenges and roadblocks can be many; but let us push agendas if the heart dictates it! Self Help groups in India would do great service to the cause of mental illness by embarking on advocacy movements.

Nirmala Srinivasan , ASHOKA Fellow is the Founder President of AMEND, Association for Mentally Disabled, Bangalore, a self help group for families of persons with psychiatric disabilities. Recently, she has started an advocacy forum called Action for Mental Illness, ACMI along with Smt. Laila Ollapally, Advocate and co-author of this paper. Contact for ACMI is acmi@vsnl.net; Visit www.acmiindia.org. ACMI is willing to provide consultancy to any organization on the methods, techniques and skills required for preparation of advocacy oriented projects. Contact, acmi@vsnl.net

Sara

By Sierra Kempster

i dont want i dont want i dont want i dont want

"Sara?"

go away go away go away go away go away

"Where are you, babe?"

im hiding and you wont find me wont wont wont

"I know you're here somewhere."

just go away leave me alone

"Ah, there you are."

oh no not now i dont want it now i cant take it now

"You know I only want to love you Sara."

why am i nodding i shouldnt nod

"I know you like to feel good, Sara."

but its wrong it hurts i know its wrong

"There, doesn't that feel good?"

nonononononononononononononononononononononononononononononono

"You were a good girl today. Here, have some candy."

i dont want your candy i want you to go away

We have found powerful expressions at the site, www.survivorsartfoundation.org, of survivors of abuse. We have come away, touched. If you are interested in survivors' art forms, do visit this site.

"Now remember not to tell mommy. You remember last time you told her she hit you and said you shouldn't say such things. She called you a bad girl for doing it, didn't she?"

yes she did

"So remember, just between us."

just between us

"That's a good girl."

Sara watches him leave. She is crying. He was wrong, it didn't feel good, it HURT, but she could never say anything, only nod. And she always cried when he left. He was right about mommy, though. Mommy didn't believe her when she told. She only hit her and told her not to be a tramp. What's a tramp? She doesn't know what a tramp is.

She pulls her underpants up and crawls under the covers and holds tightly to her teddy bear, still crying. She wants to die. She wishes she was never born. She wants everything to go away.

Her 5th birthday is tomorrow and she knows it won't get any better.