SEXO-PEDAGOGY: EDUCATION FOR PEOPLE WITH INTELLECTUAL DISABILITY AND FAMILY QUALITY OF LIFE.

B. Pavan Kumar, Department of Psychology, Andhra University

Résumé

Ces dernières années ont entraîné en Inde des changements importants dans les politiques publiques et dans les attitudes permettant aux personnes ayant une déshabilité physique et mentale de bénéficier d'une meilleure qualité de vie.

Bien que maintenant on accepte plus facilement leur droit à une place légitime dans la société, malheureusement, les attitudes de la société ont moins changé en ce qui concerne la prise en compte de leur droit à une sexualité épanouie.

Aujourd'hui encore, beaucoup de personnes refusent de reconnaître que tout le monde, y compris les personnes porteuses d'un handicap, ont besoin d'une vie sentimentale et sexuelle, éprouvent des besoins et des désirs, et ceci quels que soient leurs capacités physiques ou mentales.

En conséquence, beaucoup de jeunes adultes qui vivent avec un handicap ne reçoivent aucune éducation sexuelle, à l'école ou à la maison.

Cet article se concentre sur les différentes études et articles sur le sujet, et sur les liens entre familles et éducation sexuelle.

Mots clés : Politiques publiques en Inde, Qualité de Vie, éducation sexuelle, familles

Abstract

In recent years, in India, important changes in public policies and attitudes have resulted in improved opportunities for people with physical and mental disabilities.

Now, people living with disabilities assume their rightful place in society as the equals of non-disabled people.

Unfortunately, societal attitudes have changed less in regard to *sexuality* and disability. Even today, many people refuse to acknowledge that all people have sexual feelings, needs, and desires, regardless of their physical and/or mental abilities.

As a result, many young people who live with disabilities do not receive sex education, either in school or at home.

This paper focuses on different studies and articles related to the topic and on the link between families and sexual education..

Keywords: Public policies in India, Quality of Life, sexual education, families

Introduction

Quality of life is a complex construct which, as Schalock (1996) emphasized, can be viewed from multiple perspectives and operationalized in many ways, and which has gained increasing importance as a principle in human services. Schalock (1996) suggested that quality of life is best viewed as an organizing concept to guide policy and practice to improve the life conditions of all people, and proposed that quality of life is composed of a number of core principles and dimensions. The eight core principles forwarded by Schalock emphasize that quality of life is composed of the same factors and is important for all people, is experienced when a person's basic needs are met, and is enhanced by integration and by enabling individuals to participate in decisions that impact their lives. The core dimensions of quality of life include (a) emotional well-being, (b) interpersonal relations, (c) material well being, (d) personal development, (e) physical well-being, (f) selfdetermination, (g) social inclusion, and (h) rights.

From Quality of life to Family Quality of life

Family quality of life has grown out of work developed in a quality of life approach or framework, which over the last 25 years has become established, The trend has become fairly well accepted within the field of intellectual and developmental disabilities (Brown, 1997; Schalock et al, 2002). Much of this development started in the 1980’s (Brown, Bayer, and MacFarlane, 1989) and began to flourish in the 90’s. (Goode, 1994; Renwick, Brown and Nagler, 1996) At the beginning there was confusion over definition and approach, but over time it has settled down into a research and applied framework resulting in the production of papers recognized by bodies such as the United Nations. Quality of life approaches and indicators were put forward to and by governments. Professionals from many countries provided new ideas regarding practice, and research continued to expand and evolve (for example the Memorandum on a European Quality Principles Framework Date, 2006). All of this development was based on a notion that quality of life, as an approach, is a sensitizing concept that enables us to see disabilities in new ways and use its values, principles and concepts, to further the process of life of quality rather than to simply replace former approaches. It is argued that change of approach will also result in change of attitude by society, professionals, policy makers and agencies supporting people with disabilities and their family members. Increasingly organizations and individual professionals, including families, are beginning to adopt such an approach, even though the concepts are sometimes ill understood at the applied and policy levels and the applications might be somewhat partial. As I have indicated elsewhere (Brown, 2007), to adopt such an approach requires changes, not only in terms of our concepts and principles, but also in terms of the values espoused by policy makers as well as those of practitioners. Needs, policy and practice must fit together and their impact then assessed. For example, there needs to be a recognition that, in devising regulation standards of quality of life, one must first establish what a quality of life approach means within a particular culture, or within a particular country. That is, we need to consider how a particular society interprets the principles and values in relation to their own environment. Such an approach (re: quality of life) is now increasingly recognized in European countries, in North America, Australia, and many Asian countries such as Japan, and yet some of these concepts are still difficult for some to absorb in their own personal value system. Of course one of the issues is that one must put personal views aside in terms of professional practice when one is attempting to build and support a quality of life for an individual who may have different choices and different personal values from one's own. In other words, quality of life is highly respectful of, and sensitive to, the choices made by individuals and the values that they obtain and espouse. This becomes increasingly critical when one focuses on family quality of life and not just the individual with a disability. There probably has not been a time in human development where this approach has been so necessary in terms of service development and support practices.

Many professionals who may accept a quality of life framework have not recognized its value for families. On various occasions it was interesting for me to see the responses of sophisticated professionals who have suddenly recognized the potential of such an approach.

Family Quality of life

It is only in recent years that quality of life has been considered in relation to the family as a whole and this, within the context of the sensitizing nature of quality of life and the concepts and principles involved. All this has given rise to many questions and changes in approach, not just in research, but increasingly in regards to practice. The lives of families, where there is a person with a disability, have frequently been associated with grief, stress, and then demands, which we believe, can often not be met. Some parents, with severely disabled children, see these aspects exacerbated by a move from institutional to community living. Similarly, in some countries the moves from rural to urban living also cause family stress. Additionally, where there have been major developments in terms of disabilities and quality of life, rural areas may still remain impoverished in terms of support for family. It can also be argued that as much of the world has become industrialized, and more technically organized, the challenges for families have increased and also changed. Such change results in many dilemmas for us in terms of normalization, inclusion, and rights (see Keith and Schalock, 2000). It is made more challenging now because families often have to deal with multiple disability and increased severity of disability within the family. In deed, many such children would not have survived in the past or were placed in institutions. Further, new levels of disability have emerged for physical and environmental reasons such as drug and alcohol abuse (e.g., Fetal Alcohol Spectrum Disorder), and environmental factors, including pollution, which is argued by some to be involved in the prevalence of Autism Spectrum Disorder. In some cases many of the extreme behaviors involved are very difficult for families and care givers to manage in any type of circumstance. This is particularly true in a family environment, yet most of us believe that family inclusion is critical for these children. For that to happen however, there must be a proviso; adequate support systems musthave to be available. I believe this is the central challenge of our times, and it is one that deserves the attention of any civilized society. Without trying to make the situation appear dramatic, the situation for some families means life can become enslaved to isolated dependency even in a society whose policy is Inclusion and Rights. This enslavement we must seek to abolish. It would be unreasonable of me to make such an extreme statement unless there was clear evidence to support it. The evidence shows a wide range of circumstances and it is this range which we need to address (See for example, Special Issue on Family Quality of Life, Journal of Policy and Practice in Intellectual Disabilities 2006). Many of the parents who are in such positions would clearly recognize the situation. A quality of life approach, which is developmental, recognizes that variability in individuals and families is the norm. It also recognizes that improved circumstance results from the considered application of family choice. Both concepts require us to think of different approaches for different people because their needs are different. We are required to individualize our support system. This demands knowledge, experience and recognition that family values and behaviors need to be recognized and understood. It also requires a level of professional and ethical understanding of the needs of the person by all of those involved, and an acceptance by families that the issues are family focused not just disability focused. Families have different requirements because they have different values and different personal, economic and community resources. They also have children who differ in terms of their abilities and disabilities. Although it is also apparent that a child with a disability within a family does not necessarily give rise to unreasonable stresses, there are increasingly families where high level challenges require new solutions. This suggests that it is important that family quality of life is considered very carefully in its different shades and circumstances. Allied to this, our concept of family has changed, which is recognized in society as an issue of choices as well as circumstance (Turnbull, Brown and Turnbull, 2004). The traditional family of a father and mother and children, with extended family members of grandparents may now not be everybody's definition of a family. A family may include just a mother and a child, or a father and a child. It may also be a blended family where there are children from previous relationships. Additionally in Western Society there are frequently fewer children in a family than in previous generations, and these children are often born to older mothers who wanted to be professionally established before having children. It is common now for families to move from country to country or province to province. As a result, in many cases, the mode of communication between family members, even when they live in close proximity, has changed and in many situations is based on internet and phone communication, rather than on meeting together within one particular home or on any particular occasion. All of this has behavioral and social implications. Thus the links within and between families, and therefore the demands of families, are increasingly changing in nature as well as in their variability. This has to be recognized within service systems and policy, not only on the theoretical or systemic levels but most importantly on a very applied level. Acceptance of family views, and acceptance of their practices, within the framework of the laws of a country, need to be accepted, understood and supported and not just tolerated. These need to be understood and supported. To achieve these ends it is imperative that we recognize that supports in terms of counseling and discussion with families should be prerequisites for effective action.

Importance of a Family Quality of Life Viewpoint

Some readers will accept or be familiar with the basic literature on individual quality of life, as increasingly practiced within services for people with intellectual and developmental disabilities. It must also be recognized that as families have changed, so should our notion of services for families and their lives of quality. From a time in the Western world, where people with disabilities were sent to institution, to the present time, in which we put much effort into closing most of the institutions, we have changed our approach and belief system which, by most, is seen as a positive move. We have developed the notion of inclusion within schools; and though we do not fully practice this notion in all countries and certainly not across the lifespan, it still has many implications for a more all-inclusive quality of life approach. For example, if inclusion is practiced at an elementary school level and increasingly at a secondary school level, what are the implications for individuals with disabilities and their families once the school cycle is completed? The experience of inclusion in school raises expectations which, after graduation, are frequently not fulfilled.

Often there is no inclusive employment available after school is over and the only thing left for the individual is a traditional workshop. Sometimes however, a process of individualized planning and employment placement does take place and in some places attempts are being made to resolve such issues. Another example affecting the individual and the family is leisure and recreation, which that are often still isolated from the mainstream of the local community and family members, leaving the parents and particularly the mothers to provide the major support to their son or daughter.

SEXUALITY IN MENTALLY RETARDED INDIVIDUALS

In recent years, in India, important changes in public policies and attitudes have resulted in improved opportunities for people with physical and mental disabilities. Now, people living with disabilities assume their rightful place in society as the equals of non-disabled people. Unfortunately, societal attitudes have changed less in regard to *sexuality* and disability. Even today, there is a important difficulty to acknowledge that , regardless of their physical and/or mental abilities, all people have sexual feelings, needs, and desires As a result, many young people who live with disabilities do not receive sex education, either in school or at home. This paper focuses on different studies and articles related to the topic.

The majority of people do not ponder upon their health, usually they do this only when it is lost. Health is the cluster of circumstances: life expectations, functional status, mental welfare, social wellbeing, quality of life. Mental welfare is an important dimension of health. Basic components of mental health are cognitive and emotional functioning (Schwartz 2008). Regardless of the fact that mentally retarded individuals have a problem in recognizing, expressing and balancing their emotions, they need:

- to have privacy;
- to love and be loved;
- to develop friendships and emotional relationships;
- to learn about sex, sexual intercourse, safe sex and other issues related to sexuality (to protect themselves from sexual abuse);
- to implement their rights and responsibilities regarding privacy and sexual expression;
- to enter marriage and become parents;
- to develop personal sexual identity in accordance with age, social development, cultural values and social responsibility (Dorsey et al. 1998, Walsh et al. 2000, Štifanić & Dobi-Babić 2000).

It is known that the issue of sexuality is very important, particularly to young people. Healthy young persons very often mutually exchange information on this topic and get educated in this way, as well as through the media and family. We are witnesses that sex education is a political issue as well. Besides, in some countries sexuality is used as a tool for reducing the rights of women, particularly when certain psycho physical restrictions are present (Gardner 2002, Casas 2009). Moreover, investigations show that very few schools of medicine have programs to prepare physicians and other medical staff for delivering the courses of sex education (Dunn & Abula 2010). Young disabled people cannot talk about sexuality with their peers because they attend special schools or classes for disabled persons. In these special school programs there is usually no talk about sexuality, although they are also individuals with sexual needs. Adolescents with mental retardation experience through puberty the same hormonal storms as their healthy peers. Their parents are daily confronted with numerous problems and thus simply do not have either time or strength to introduce conversation on the topic of sexuality. Exclusion of sex education as a part of the educational cycle for this group means discrimination and depreciation of their essential human rights. It must be mentioned that due to all these facts such persons are more prone to sexual abuse than the non-retarded, while unwanted pregnancies and sexually transmitted diseases are very frequent (Walsh et al 2000, Gust et al. 2003, Murphy & Elias 2006, Carpenter 2002).

Myths and Facts about Sexuality and Disability

Many people believe myths about the sexuality of people who live with disabilities. Common myths:

- People with disabilities do not feel the desire to have sex.
- People with developmental and physical abilities are child-like and dependent.
- People with disabilities are oversexed and unable to control their sexual urges.

Myth 1: People with disabilities are not sexual. All people—including young people—are sexual beings, regardless of whether or not they live with physical, mental, or emotional disabilities. And, ***all*** people need affection, love and intimacy, acceptance, and companionship. At the same time, children and youth who live with disabilities may have some unique needs related to sex education. For example, children with developmental disabilities may learn at a slower rate than do their non-disabled peers; yet their physical maturation usually occurs at the same rate. As a result of normal physical maturation and slowed emotional and cognitive development, they may need sex education that builds skills for appropriate language and behavior in public. In another example, paraplegic youth may need reassurance that they can have satisfying sexual relationships and practical guidance on how to do so.

Myth 2: People with disabilities are childlike and dependent. This idea may arise from a belief that a disabled person is somehow unable to participate equally in an intimate relationship. Societal discomfort—both with sexuality and also with the sexuality of people who live with disabilities—may mean that it is easier to view anyone who lives with disabilities as an 'eternal child.' This demeaning view ignores the need to acknowledge the young person's sexuality and also denies her/his full humanity.

Myth 3: People with disabilities cannot control their sexuality. This myth spins off the other two—if people with disabilities are neither asexual nor child-like, then they perhaps they are 'oversexed' and have 'uncontrollable urges'. Belief in this myth can result in a reluctance to provide sex education for youth with disabilities. The reality is that education and training are key to promoting healthy and mutually respectful behavior, regardless of the young person's abilities.

Why Should Parents Be Concerned about Sex Education for Their Disabled Children? Parents are, or should be, their children's primary sex educators, but many parents are afraid to talk to their children (disabled or not) about sex. Parents often fear that: 1) talking about sex will encourage sexual experimentation; 2) they (the parents) don't know enough to handle questions appropriately; and 3) their children already know too much or too little. In addition, parents of children who are living with disabilities may feel that their children are potential targets for sexual abuse or exploitation. Or the parents may fear that their children may be unable to appropriately express their sexual feelings.

In short, parents often fear that talking about sex may cause problems. But, parents need to assist any child—regardless of her/his abilities—to develop life skills. For example, without appropriate social skills, young people may have difficulty making and keeping friends and feel lonely and 'different'. Without important sexual health knowledge, young people may make unwise decisions and/or take sexual health risks.

The sex education is not only considered with teaching sexual act but also with the associated factors in life like family, Role to be played in the family, Duties to be performed like taking care of their children, husband/wife, relationships. It also discusses the importance of teaching the associated factors for a better quality of life. It also discusses about the drawbacks in the quality of life if a mentally challenged is bound in a relation without any or proper sex education.

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