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ORIGINAL PAPER

Systems Theory and the Development of Sexual Identity for Individuals with Intellectual/Developmental Disability

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Abstract The purpose of this paper is to examine social systems theory as it relates to the inclusion of disenfranchised populations into the larger social system by enabling these populations to receive education and resources which can allow them to develop skills needed to achieve inclusion. Specifically this study is concerned with using elements of social systems theory to develop a sexual education program for a population identified with an Intellectually/Developmentally Disability (ID/DD). In order to do this, it is necessary to work within the family or caregiver system where these individuals live and function. Caregivers must be helped to recognize the potential for inclusion in this area of life for this population, and educational tools appropriate to the developmental and cognitive levels of the participants must be made available. Acknowledgment of the individual's role within the system and understanding of the individual's experience of that systems interaction with the environment and with other systems is primary in developing effective programming which can increase the quality of the participants' interactions and relationships, making life a more productive and more satisfying experience.

Keywords Systems theory · Intellectual disability · Developmental disability, sexuality

Introduction

Systems theory addresses the equity of value of all participants within a system. This is not always easily apparent to outside observers, or even at times to those within the system. Inequities appear based on ability and hierarchically assigned power; however, as systems grow and change these inequities often prove to be temporary and fluid. In the task of maintaining a sense of order within the system, every role has its value, and the loss of one whose role may have seemed of lesser value can have as great an impact on the total system as the loss of one whose role had seemed of more value. Even in the midst of chaos

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and dysfunction, the balance and order that living systems strive to maintain is dependent upon every participant playing their part [1].

Persons with intellectual and/or developmental disabilities (ID/DD) have the same rights and needs for access to comprehensive health care programs, including sexual health, as others within the population. Unfortunately, many of these individuals are viewed by others within the system as being perpetually child-like, and this image results in the denial of opportunities to learn the skills needed to make informed choices regarding sexuality. The result is often an increased vulnerability to abuse and/or assault [2].

These individuals are often dependent on caretakers (frequently parents or other family members) for meeting their daily needs. Because this is true, and because these caretakers often have difficulty coping with the striving by these individuals for greater independence, it becomes essential that the caregiver/family member be included in the effort to develop programming to assist these individuals in dealing with relationship issues as well as in other aspects of training. The more the caretaker/family member is able to understand and accept the individual’s efforts and needs, the more likely they are to support the individual appropriately in their efforts. For this reason, any programming developed to assist the individual with ID/DD to take a greater part in social interactions must include an initial component for training the caregiver/family member to better understand the need and the ability of these individuals.

Study of Literature

Hierarchies are necessary within systems to maintain order. Ideally these hierarchies exist with an understanding of the equity of the total system, and function to maintain order while still respecting value and encouraging growth, allowing participants to rise within the hierarchy as development of abilities and knowledge increases. This is not, however, always the case. There are abuses of power within some systems, resulting in biases which prevent the acknowledgment of personal value for many within the system [1].

Reynolds et al. [3] address concerns related to stereotyping and its effect on the ability of individuals within a system to achieve appropriate levels of power. The link between stereotyping and power suggests that “stereotyping is an instrument wielded primarily by the powerful in a way that furthers their interests to the detriment of the powerless” (p. 275). Impressions of others, if they are to be valid, take time and effort. For many, the time and energy required to make this effort are for whatever reason determined to be too great a demand, and these individuals chose to rely on social categories to make stereotypical judgments of others. “It should follow that the desire to be accurate should encourage attentional investment…and the desire to be accurate has been linked with interdependence” (p. 275). Studies have tested the prediction that interdependence brings a need for prediction and control, resulting in interdependent individuals that will care more about accuracy and less in the stereotype (p. 275). The authors found that for individuals existing in systems with open boundaries, accuracy in impression of other was more highly valued, while those existing in closed systems tended to rely more on stereotyping and are less willing to invest the time and attention to view others more accurately. In addition, those in open group systems tended to view others from outside the group in a favorable light based on higher status group members’ views. It is suggested that “whether power reduction of power enlargement occurs within an organization depends on the way the relationship between groups is defined—either intergroup (us vs. them) or intragroup (“we are all in this together”). The powerless and powerful may judge the social context and group relations differently depending on their group interests, goals, and motivations" (p. 286).

Bernik [4] considers the limitations placed on the political systems established within the larger society to regulate such concerns. These systems are often expected to regulate the separate smaller systems that make up the larger society, but are ineffective in doing so due in great part to the inherent limitations, leading to disenchantment rooted in ongoing change in political rules and the inability to live up to the growing needs of changing societies. "The emergence of a polycentric society, i.e., of a society composed of highly autonomous but nevertheless interdependent functional subsystems, is a long evolutionary process. It means that the political system as a risk-absorbing center of society will long be exposed to demands which largely exceed its regulative potential. The task of moderating the contradictions of societal transformation, which is ascribed to the political system, could intensify contradictions and instabilities in the political system" (p. 354). Certainly evidence of this limitation to regulate systems can be seen in efforts to legislate against discrimination, which, while effective to some degree in the public sector, has not eliminated the inequities faced by those groups who are the victims of discrimination.

Colomy [5] collected works also examining the political structure of social systems as they affect the integration of parts into the whole of society, and often demonstrating the same limitations in the ability to do this. In fact there is evidence that the power structure inherent in political systems is often too open to abuses and may only change the language with which the system refers to its discriminatory practices, while supporting ongoing abuses in power and ongoing inequality within the larger social structure. The use of media to reach the masses with political messages is one example of the political systems inconsistency in providing needed understanding of policy. "Articulation of televised political campaigning with the traditional concept of the body politic would require institutions that allow the public to test the claims of those who would use the media to create influence; authentic two-sided debate" (p. 211).

Certainly stereotyping has been a barrier for many individuals identified as being in the disabled population within the social context. Michailakis [6] argues that disability is a function of perspective as drawn from the specific systems view from which one observes the disability. "The particular ways in which social systems observe and communicate about disability determines exactly its meaning in the different systems, how the group is treated and the problems they face. Just like archaic societies, organized into segments; families, clans and tribes, the structure of stratified societies—that is societies structured in hierarchical layers—is governed by the principle of placing people in different groups; in this case in different layers. In segmental as well as hierarchical societies, the relationship between society and the individual is determined by total inclusion. Individuality and social position are identical. Belonging to a tribe, family, corporation, or estate encompasses all aspects of an individual. Now the central thesis of systems theory is that, with the formation of functionally differentiated society, the very principle of social differentiation—placing individuals in families or social layers—has become obsolete; it is no longer groups of people that are distinguished but types of communication" (p. 220).

In the differentiation of groups, Michailakis [6] argues, the demand for inclusion implied a need for new ways to communicate regarding the social problems represented by those with disabilities. He says that social change has led to the identification of certain persons as disabled who once would have had no such label. This relates in large part to the social distinctions made with the rise of capitalist society and its demands for "work ability," leading to the labeling as disabled of those unable to perform demanded work tasks in the age of technological labor.

A phenomenon that has been observed repeatedly in studies of discrimination within systems is the passivity of victims of discrimination in the face of inequality. Louis and Taylor [7] studied this phenomenon, specifically focusing on the apparent individual response patterns of these victims. The study started with observations that individuals experiencing discrimination often avoided group support in dealing with issues of discrimination, choosing instead to deal individually and usually ineffectively with these issues as they arose. Their conclusions suggested that individual response grew out of the expectation of individualism, especially as it is presented in the United States. It also was suggested that many times failure to participate in collective efforts to deal with discrimination was the result of limited leadership and lack of clear group goals.

Certainly the group in which participants initially find support and validation is expected to be the family system. Support is a primary function of any group, especially the effective family group. Dunst et al. [8] address the effects of family on adolescents, specifically pregnant teenagers. The study looks at the effects of stress in crisis on the health and wellbeing of the pregnant teen, and the role social support plays in providing a buffer against extreme stress. Results of the study demonstrated that “(a) psychological well-being and family climate during the teenager’s pregnancies; and (b) birth related problems, mode of delivery, emotional and physical well-being, and commitment to the care of their children after delivery, were related to a number of interpersonal, family-related, and extra family (support) characteristics” (p. 45).

After the family, the community is the basic structure of the social system in this country. When the community is functioning properly, the education, socialization and health of its residents will be enhanced. Because this is true, it is imperative that community leaders evaluate their communities and plan for needs provision [9].

Reicherter and Billek-Sawhney [9] addressed the needs of older individuals, another segment of the population often disenfranchised due to age related issues including health, financial limitations, etc. These issues can often lead to the loss of familiar home placements, as well as increasing isolation within the community. “Retirement communities, assisted living, and nursing homes are frequently designed to accommodate the special social and physical needs of the older population. However, for the older adult with advancing medical needs, these unfamiliar surroundings and frequent displacements can be very unsettling and detrimental to their health” (p. 300). Continuum of care communities as addressed in the article discussed here make an effort to create a viable community for these individuals, providing resources to assure the meeting of needs while encouraging an ongoing social interaction to maintain the synergy of the community through individual connection.

Norlin and Chess [10] address the need of the caretaker to understand the systems and subsystems within which client participants exist, as well as the suprasystem or environment in which the systems exist. In order to effectively meet the needs of the individual, a grasp of the system is essential. “Many of today’s problems are so massive and so destabilizing to society that intervention at any one level is insufficient, for example, the rising tide of violence. Intervention is required at all levels—the individual, group, family, organization, community, and the society itself” (p. 347). Intervening at only one level will fail to meet the participant’s needs, as support in one level may be met with discrimination or opposition in another which will negate any positive effects from the limited support. It is essential for caregivers and other professionals who work with the disabled and other disenfranchised groups work with these people by relating to their systems as a whole and acknowledging the importance of those systems and subsystems to the integrity of the individual if any work done is to be truly effective.

The primary human need met by the system is that of belonging. Affiliation with a system is the method by which this need is met. Affiliation may be compulsory, through kinship or citizenship, or they may be voluntary, as in marriage, membership or ownership. Four main types of systems one affiliates with are family, state, voluntary organizations, and business enterprises. Ahrne [11] examines how the same action may take on different meanings and levels of importance when enacted in different subsystems.

Discussion

Systems theory is applicable to almost every aspect of human experience, from family to political party to national identity, with a vast number of systems falling in between these systems. Affiliation with a system provides identity and validation. It says that the individual is capable of performing the tasks required to maintain affiliation with that system. But what of those individuals who cannot perform as expected to establish and maintain affiliation with societally valued systems? What allows them to find belonging, one of the basic human needs? What gives them a sense of self-worth and validation as human beings? What type of value system can they be expected to adopt when they are denied access to the source of support and training considered a right by the majority?

Those within the population who are labeled as developmentally or intellectually disabled are often separated from the mainstream population, maintained within the primary family or perhaps placed in institutional settings. In either case, it is likely that the "disabled" individual will be further disabled by denial of access to the flow of information and communication common to the general public within the larger social system. Marked as less capable, these individuals are denied control in their own lives and are assumed to be in need of constant management by caregivers and other professionals. While it is true that these individuals may require a larger amount of support to function adequately, this should not be seen as a reason to assume they are not capable of functioning. If, instead of maintaining them at a minimal level of functioning, the caregiver or professional involved in their lives can provide appropriate stimulation and training to help them increase their functioning ability, they are often able to achieve far more than had initially been expected.

Determination of what can be achieved by the individual with disability is in large part a function of systems expectations and values. What is presented as a worthy undertaking by the family of origin is likely to become the perceived reality of what is worth working toward. While the individual with a disability may take additional effort and training, such effort is more likely to seem worth making if the family system is supportive and finds a means of providing the additional supports needed.

This was a primary consideration when this author began working on developing a program in sexuality education for individuals with ID/DD. The reason for considering such a program is twofold. Lack of understanding about sexuality, both by the individual and caretakers of that individual, can prevent the fulfilling participation in a primary aspect of human life, that of intimacy within a relationship. In addition, lack of adequate education in sexual mores frequently results in incidents of sexual abuse, and indeed the rate of sexual abuse and assault perpetrated against this population is significantly higher than among the "normal" population [2]. The response to this victimization tends to be different based of gender. Women among the group identified as being disabled tend to respond with a somewhat passive, accepting attitude reflective of their lower degree of power within the abusive relationship. They often assume the abuse is normal, and when they object they tend to be discouraged from speaking about the subject. Because of their place on the power structure within their system, they usually comply with abuser demands to "keep quiet." Male victims, on the other hand, are more likely to imitate the abusive behavior and victimize others. Often when these men are reported to be involved in perpetration of sexual offenses, their status as disabled individuals prevents them from being convicted. The result of both scenarios (male and female) tends to be the repetition of sexual aggression as no intervention to change the understanding of the individual is likely to take place. It is important to note that in both scenarios, the individuals involved often assume that sexual aggression is a normal behavior based on their experience within their respective systems [2, 12–16].

Because there is a difference in ability and learning style between individuals with ID/DD individual and other members of the population, efforts to educate these individuals must be designed to meet the comprehension needs of those involved and should include techniques of teaching likely to anchor concepts in their consciousness in a manner adequate to allow retention and assimilation. It is, however, first imperative that those within the individual's system, who are most influential, including primarily parents and other caregivers, be educated in the needs and abilities of the cared for individual in the area of sexuality. Because these caretakers often think of their disabled family member or dependent as being child like and removed from thoughts of sexuality, it becomes necessary for them to better understand the reality of sexual development as it truly affects most of these disabled individuals. Their refusal to accept this or to support the person with disability in the effort to develop improved sexual understanding can sabotage any effort to aid the individual, as the influence of the caretaker may well be so much a pert of the individual's internal acceptance system that it cannot be over-ridden. Because such abuses of power, often done in the belief that "it's for the best," are common among disenfranchised sections of the population such as the ID/DD, winning over the power structure as embodied in the caretaker becomes imperative if change is to be accomplished [2].

Anderson et al. [1] explain this power relationship thusly: "A has power over B to the extent that he can get B to do something B would not otherwise do…A's power over B is (a) directly proportional to the importance B places on the goals medicated by A, and (b) inversely proportional to the availability of these goals outside the A–B relation…Such power is based on 'manipulating rewards and punishments important to the other person" (p. 126). In the relationship between the individual with ID/DD and the caretaker, the caretaker's goals are usually related to maintenance of a protective environment which often separates the individual with a disability from the larger social system. This goal often precludes goals the individual with a disability might desire, but because the rejection of the caregiver goal could lead to loss of not only belonging, but even more basic survival needs related to safety and survival, the individual with ID/DD may be trapped in the caregiver's preferred setting. Isolating the individual with ID/DD away from the larger system and the environment in which that system functions is the ultimate consequence if the caregiver cannot be convinced of the benefits of opening the system to allow new experiences. For these reason educational opportunities, including education in sexuality must be presented in a non-threatening and rational manner to the caregiver. If the caregiver can see such programming as beneficial to the cared for individual, he or she is more likely to accept that individual's participation, thus allowing an opening for the disabled individual to reach through the limiting boundaries of his or her system to explore and experience suprasystem in previously denied ways. If supplied with the right support and informational tools, this expanding into the environment should be a freeing and positive experience not only for the individual with ID/DD, but also for the caretaker who had initially reinforced closing those boundaries.

Having moved into newer experiential territory, the individual with ID/DD needs to be supported in learning the decision making skills which will enable them to establish new relationships, including sexual relationships. Currently community involvement for this population often means placement in group homes or work in sheltered workshops. This practice again limits experience, placing the population identified with ID/DD in smaller communities composed mainly of others with similar disabilities. While this allows them to cultivate relationships with others of shared experience, it denies them access to experiences shared by the mainstream population. This separation from the mainstream can reinforce the sense of devaluation among populations identified with disabilities and is accompanied by feelings of isolation and loneliness [2].

Inclusion in the larger population is important for this group, and part of learning to belong to a social group is learning to understand expectations about behaviors. For the individual with ID/DD, sexual behavior is often an obstacle to inclusion in mainstream social systems. The solution to this is exposure to those who model accepted behaviors, as this population tends to learn best through viewing appropriate behavioral models, then being encouraged to practice appropriate behaviors in the learning setting. This often means pointing out inappropriate behaviors, explaining how these behaviors create alienation or other negative consequences, demonstrating more acceptable behaviors, then allowing opportunity to practice those behaviors. This includes sexually suggestive comments, boundary intrusion, and other common public behaviors which often result in rejection by mainstream society [2].

Another aspect of sexuality education important for this group is the opportunity to ask questions about concerns and receive honest answers. Often this requires an initial offering of information as many may not know what questions to ask initially. The concerns about how to meet people, how to date, and how to introduce new people to those in the individual's primary support system are as important, as questions about birth control and sexually transmitted disease to many of these individuals. All are valid aspects of developing intimate relationships and allowing the individual to feel that they are developing some control over their life experiences. All need to be answered honestly and with equal respect for the desire to know [2].

Individuals identified as having ID/DD share the right to sexual freedoms enjoyed by the mainstream populace, including the right to be informed about sexuality, the right to enjoy sexual activity (assuming the capacity to give consent is present), the right to contraceptive access and use, the right to information on sexually transmitted diseases and related preventative measures, the right to form sexual relationships and marry (again assuming ability to consent), the right to parenthood, and the right to be protected from sexual abuse [2]. These rights can help the individual feel a greater sense of inclusion in the social system and a greater sense of self as fully human. In determining the ability to consent as used above, one should be able to make choices based on knowledge, communicate willingness to participate in the action involved, and be free from coercion of those with greater power.

The majority of sexuality education programs currently in existence have been developed with no input from individuals with ID/DD. Failure to seek input from those whose lives will be affected by this programming results in limited understanding of self-perceived needs and so limited responsiveness to those needs. To develop a truly effective program it is necessary to have a free flow of communication between information provider and the individual seeking knowledge. While there is a tendency, and justifiably so, to assume the provider has a greater fund of information to contribute in a learning situation, it is an abuse of power to assume that the recipient of this knowledge has nothing to contribute in turn. Indeed, by seeking information from the students regarding their perception of needed information, one is more likely to gain a commitment to the process. At the same time, the individual seeking knowledge begins to feel an affiliation to the process and so begins the establishment of ties to this new system of learning.

All humans need to feel they belong. All humans want to know they are heard. Seeking input from those with the greatest need about their perception of their needs seems only a logical and natural approach to entering into an educational relationship. Engaging the total system, especially when that system retains significant power over the individual involved, is a logical step in assuring the highest quality of interaction for the individual participant.

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