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Serving Youth with Physical Deformity in Canadian Schools: Ethical Guidelines for Non-Discriminatory Practice

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Abstract: Physical deformity has a number of serious affects on an individuals psychological and social functioning. In order to help psychologists and other professionals involved in the education of youth with physical deformity, we have interpreted the Canadian Psychological Association's (CPA) Guideline's for Non-Discriminatory Practice in this context. The general principles of the Guidelines for Non-Discriminatory Practice are consistent with those of the Canadian Code of Ethics for Psychologists (CPA, 2001) and include: I. Respect for the Dignity of Persons, II. Responsible Caring, III. Integrity in Relationships, and IV. Responsibility to Society. In addition, several examples of ethical dilemmas that may arise through involvement with students with physical deformity are presented and discussed.

Key words: *physical deformity, ethical practice, children & youth, schools*

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1. Introduction

There are a vast number of physical deformities that affect children and adults alike. These include such things as cleft lip, pectus deformities, scoliosis, burns, and skin conditions such as vitiligo, and port wine stains. It is estimated that one percent of adults live with a physical deformity (THOMPSON & KENT, 2001). While no such statistics could be found for children, the fact that many of these deformities are congenital (such as port wine stains and cleft lip) or typically develop in adolescence (such as scoliosis and many pectus deformities) suggests that many children and adolescents are also living with physical deformity (EMERY, 2001; FORSTENZER & ROYE, 1988). The extant literature indicates that physical deformity has multiple effects on an individuals social and psychological functioning. Persons with physical deformities are at a greater risk for anxiety, depression, low self-esteem and social withdrawal (EINSIEDEL & CLAUSNER, 1999; SARIMSKI, 2001; THOMPSON & KENT, 2001). [1]

Given the serious nature of the effects that physical deformity can have on a child, it is important that educators and other professionals working with children and families be prepared to include and support these individuals without discrimination. Psychologists working with schools, or children and their families have a responsibility to collaborate with educators, and other professionals, and to inform practice in this area through the sharing of information and strategies. The Canadian Code of Ethics for Psychologists (CPA, 2001) is an important

reference for school psychologists and other professionals who work with children affected by physical deformity. [2]

2. Physical Deformity

The effects of physical deformity on an individual have been examined through research from two different perspectives. The first approach has examined the way in which others perceive an individual with physical deformity. The second has examined the thoughts, perceptions, and feelings of individuals with physical deformity (THOMPSON & KENT, 2001). [3]

The extant literature from the first perspective indicates that physical appearance plays an important role in the way an individual is perceived by others. Attractive people are perceived as more competent, more intelligent, and better adjusted (HILL-BEUF & PORTER, 1984; THOMPSON & KENT, 2001). In contrast, individuals with a visible physical deformity are often met with uncertainty, if not hostility, in social situations (CLARKE, 1999). A physical difference is a novel stimulus and others often become caught between curiosity and the knowledge that staring is not socially acceptable. This "can lead to uncomfortable or curtailed interactions between physically handicapped and non-handicapped persons" (LISKEY-FITZWATER, MOORE, & GUREL, 1993, p.16). [4]

Physical deformity can have a particularly significant effect on the social interactions of children and youth. Research has found that "appearance is the most common focus of interpersonal teasing in childhood" (CASH, 1995, p.123). In early adolescence, appearance becomes particularly important to self-concept as bodies begin to change (ANDERSON, 1982; HILL-BEUF & PORTER, 1984). Appearing different is greatly feared by many adolescents as they begin to focus on clothing, and other aspects of appearance (LISKEY-FITZWATER et al., 1993). As with individuals without physical deformity, it is expected that children and youth with a physical deformity would experience a similar focus on appearance and a certain amount of social stigma as a result. [5]

Research focused on the thoughts, perceptions, and feelings of individuals with physical deformity has yielded several consistent results (THOMPSON & KENT, 2001). As a result of their physical deformity individuals experience heightened social anxiety, embarrassment, feelings of stigmatization, social withdrawal, depression, and low self-esteem (EINSIEDEL & CLAUSNER, 1999; KENT, 2000; SARIMSKI, 2001). Beyond these findings, one of the most prominent themes in the extant literature is that there is great variability in the way in which individuals react and adjust to living with physical deformity (ANDERSON, 1982; KENT, 2000; SARIMSKI, 2001; THOMPSON & KENT, 2001). Research indicates that this variation in response is the result of a number of interacting factors, some playing more important roles than others (ANDERSON, 1982). These variables include the severity or visibility of the deformity, demographic factors such as age, personal qualities such as values, anxiety level, competency and social skills, and finally the amount and quality of social support that an individual has access to. [6]

Research has yielded mixed results on the role of the severity and visibility of a physical deformity in shaping the individuals response to their physical difference. Overall it is generally agreed upon that severity is far less relevant to overall coping and adjustment than visibility (KENT & KEOHANE, 2001). A more visible physical deformity will result in an increased incidence of social stigma, however, this daily confrontation will also force the individual to adapt to their differences and develop responses to social reactions (EINSIEDEL & CLAUSNER, 1999; THOMPSON & KENT, 2001). Individuals with less visible deformities will face less social stigma, but will likely resort to camouflage methods of coping and will have more difficulty dealing with those situations in which their deformity is exposed, such as the high school locker room, the swimming pool, or within intimate relationships. [7]

Studies have also shown that age can play a role in determining the degree of effect that a physical deformity can have on an individual. Adolescence has been identified as the most difficult period for individuals living with deformity (ANDERSON, 1982), particularly because at that age they place "more importance on appearance than any other age group" (LISKEY-FITZWATER et al., 1993, p.20). Evidence suggests that very young children are relatively

unaffected and older adolescents tend to manage more successfully through focusing on their abilities and positive peer relationships (HILL-BEUF & PORTER, 1984). [8]

Far more important factors than age and severity are an individual's personal qualities such as their self-concept, values, competency, attributions and social skills (ANDERSON, 1982; THOMPSON & KENT, 2001). Research involving physical deformities that develop or occur later in life suggests that those individuals with high self-esteem, who placed value in their personal strengths and talents, were able to cope more effectively with the change to their appearance than those with a previously low self-concept, who highly valued appearance (ANDERSON, 1982). Literature also indicates that those individuals who tend to attribute the negative words or actions of others to their physical deformity will have much higher social anxiety than those with more positive attributional tendencies. Social skills have also been shown to be a strong positive factor in enabling individuals to adjust to and cope with physical deformity, as they allow for positive social experiences in spite of the individual's physical difference (THOMPSON & KENT, 2001). [9]

Finally, social support is the most effective variable in contributing to the positive adjustment of individuals living with a physical deformity. A strong network of social support is consistently found to result in better adjustment and more successful outcomes (CLARKE, 1999). Social networks have a strong influence on an individuals personal values and attributional tendencies. When ones social group highly values intelligence and abilities over appearance, it is much easier to adjust to physical differences (FORSTENZER & ROYE, 1988). [10]

Physical deformity has serious effects on the social and psychological functioning of students, and there are a wide variety of factors that can contribute to either positive or negative adjustment. Therefore, it is important for educators to have an understanding of these effects in order to create a supportive and optimal learning environment. Currently there are few resources for Canadian educators on how to best meet the needs of this particular population. Canadian psychologists, on the other hand, have an excellent resource in the Canadian Code of Ethics for Psychologists (CPA, 2001). Psychologists, particularly those working within educational settings and with individuals affected by physical deformity, have a responsibility to collaborate with, and inform the practice of, educators. Through sharing the valuable information and strategies contained in the CPA Code of Ethics, psychologists can help to improve the educational environments for children and youth with physical deformities. [11]

3. Canadian Code of Ethics and Guidelines for Non-Discriminatory Practice

The CPA Guidelines for Non-Discriminatory Practice were created in response to the changing demographics and increased diversity of Canadian society. As society becomes more diverse it is important that psychologists, along with other professionals, become aware of, and develop a respect for the varying needs of special populations (ROBERTS, PETTIFOR, CAIRNS & DEMATTEO, 2000). The CPA Code of Ethics (2001) is composed of four ordered principles: (I) Respect for the Dignity of Persons, (II) Responsible Caring, (III) Integrity in Relationships, and (IV) Responsibility to Society. The guidelines can be applied to a variety of specific diversities. For example ROBERTS et al. (2000) specifically applied these guidelines to work with children infected with HIV/AIDS. For the purposes of this paper, the guidelines have been presented as they apply to the work of both educational and psychological professionals involved with students affected by physical deformity. This is followed by a discussion of the various ways in which these ethical principles can be applied to potential dilemmas involving students with physical deformity. [12]

The CPA Code of Ethics (2001) outlines a framework for ethical decision making that Canadian psychologists are expected to follow when confronted with an ethical dilemma. The four ethical principles are ordered, such that, in an ethical dilemma which puts one principle in conflict with another, more weight should be given to the principle with the higher ranking. For example, if Principle I (Respect for the Dignity of Persons) is in conflict with Principle II (Responsible

Caring) psychologists should proceed with ethical decision making by placing more weight on Principle I. [13]

3.1 Principle I: Respect for the Dignity of Persons

The principle of Respect for the Dignity of Persons requires psychologists to actively demonstrate an understanding and belief that each individual is, first and foremost, a person of value. The Guidelines for Non-Discriminatory Practice state that psychologists must "appreciate that the innate worth of human beings is not enhanced or reduced by … any preference or personal characteristic, condition, or status" (CPA, 2001, p.268). Therefore, it is of the utmost importance that psychological professionals working with youth affected by physical deformity appreciate that the innate worth of these individuals is not reduced by their condition. As the vulnerability of youth with physical deformity increases and their power to control their environment decreases, professionals have an increased responsibility to safeguard their rights. Professionals must take special care to respect the privacy and confidentiality of these youth. Professionals do not practice or condone any form of discriminatory action towards this specific population. Finally, professionals must be conscientious in monitoring how they demonstrate respect to children and youth with physical deformity. [14]

3.2 Principle II: Responsible Caring

The principle of Responsible Caring requires professionals to demonstrate an active concern for the welfare of the youth with physical deformity with whom they work. There is an additional responsibility to ensure that these individuals have equal access to the benefits of educational and psychological knowledge and services, regardless of their condition. Responsible caring addresses both the short and long-term welfare of these students. It requires an interest in empowering these young people to pursue equal opportunities in mainstream society through encouraging personal coping skills and effecting social change. [15]

Professionals must recognize that in order to adequately care for youth with physical deformity, they need to be competent in their professional activities. Competence requires specific knowledge of deformity and its various effects on individuals. It also requires "self-monitoring of one’s own knowledge base, personal values, experiences, biases, attitudes, and socialization, which influence how one practices" (CPA, 2001, p.269). Professionals working with youth with physical deformity are responsible for maintaining competence and arranging activities amongst colleagues to maintain and increase the competence of all individuals involved with this special population of students. [16]

3.3 Principle III: Integrity in Relationships

The principle of Integrity in Relationships requires that, in their interactions with students affected by physically deformity, professionals are honest, open, objective, and accurate, and avoid deception, bias, and inaccuracy. A professional’s individual characteristics, values, and beliefs influence his or her assumptions, observations, and interpretations surrounding physical deformity. Therefore, professionals are responsible for managing situations where conflict arises between their interests and the interests of the youth with physical deformity with whom they work. [17]

3.4 Principle IV: Responsibility to Society

The principle of Responsibility to Society requires that professionals demonstrate caring and concern for the welfare of all human beings in society. "They may choose for themselves the most appropriate and beneficial use of their time and talents to help meet this collective responsibility" (CPA, 2001, p.269). Professionals who have been involved with youth affected by physical deformity may use this knowledge to influence social policy, or to provide public education regarding the impacts of deformity. It is also appropriate for professionals to be involved in advocating or lobbying for the rights of individuals with physical deformity. If social

policy and societal attitudes seriously ignore or violate the ethical principles of respect, caring and honesty, to the harm of youth with physical deformity, then professionals have a responsibility to advocate for change to occur as quickly as possible. There is social injustice when youth with physical deformity are devalued or oppressed and it is the ethical responsibility of professionals to use their knowledge to affect social change. [18]

4. Ethical Dilemmas Involving Students with Physical Deformity

The ethical principles outlined above, along with the guidelines for ethical decision making presented in the Canadian Code of Ethics for Psychologists (CPA, 2001), can be highly useful tools for professionals in educational settings encountering ethical dilemmas involving students with physical deformity and for researchers in such situations. There are countless dilemmas that may present themselves in school and school-based research; however, only a few will be discussed within this paper. The purpose of the following discussion is to exemplify the practical application of the CPA guidelines for Non-Discriminatory practice to the work of professionals involved with youth with physical deformity. [19]

It is important to acknowledge that non-discriminatory practice should not necessarily be interpreted as treating everyone the same. The belief that all individuals, regardless of personal characteristic, condition, or status, benefit equally from the same educational approaches and environments is a mistaken assumption (TRUSCOTT & CROOK, 2004). Professionals demonstrate competence by remaining open minded in their approaches to students with physical deformity, and becoming aware and knowledgeable of the effects that deformity has on their students. The first ethical principle, *Respect for the Dignity of Persons*, suggests that due to the increased vulnerability of these particular students, professionals have a responsibility to safeguard their rights; this may involve unique treatment (CPA, 2001). The discomfort that some students with physical deformity face in school change rooms presents an example of the type of dilemma that may require reference to this principle. [20]

Many individuals live with physical deformities that can be camouflaged with clothing. These youth are able to avoid unwanted attention from others, regarding their physical difference, through wearing clothing that masks their deformity. For these individuals, being required to change their clothing for physical education classes or being required to wear a certain type of clothing as a school uniform can cause great distress and often forces them to expose their physical deformity to peers. Professionals who choose to respect the dignity and privacy of these students might offer alternative arrangements that would allow them to fully participate without having to expose their deformity to peers. It is important to note that not all students with deformity would be interested in alternative uniform or changing arrangements, thus, this must be a decision that addresses the unique interests of the individual student. [21]

The ethical principle of *Responsible Caring* suggests that professionals need to address both the long-term and short-term welfare of their students (CPA, 2001). The previous example addresses an immediate situation for the student, but does little to impact long-term well-being. Professionals and researchers are also able to demonstrate competence through an active understanding of the many variables that contribute to positive adjustment among individuals with physical deformity. These include the severity and visibility of the deformity, age, self-concept, personal values, competency, social skills and social support. Although there is little that professionals and researchers in educational settings can do to change the severity and visibility of the deformity or the age of the student affected, they can be active in fostering many of the other variables. Within their interactions with students, professionals and researchers can actively encourage strong self-concepts and social skills; they can also demonstrate values that focus on the students' abilities and talents. Finally, school professionals and educational researchers can work to foster a rich social environment that provides strong social support networks for all of the students. This requires a keen awareness of the social activity and relations that exist within the school, and an effort on the part of all staff to foster a positive and nurturing environment. Researchers, too, can contribute to such a positive and nurturing environment while they are working in the school setting. Exposing youth to this type of positive social support

may encourage them to seek out similar support networks when they leave the school environment. This is an important area of work for professionals, as social support is known to be the strongest influence towards a positive adjustment to physical deformity (FORSTENZER & ROYE, 1988; THOMPSON & KENT, 2001). [22]

The principle of *Integrity in Relationships* calls for professionals and researchers to be open and objective and to manage situations in which there is conflict between their own interests and those of their students (CPA, 2001). One example of a situation in which a student with physical deformity may have differing interests from the educational professionals working with them is in the case of surgical correction options. For some individuals with physical deformity there are surgical procedures available to correct, or at least reduce the severity of, their physical deformity (THOMPSON & KENT, 2001). For many youth, these cosmetic surgeries will require numerous medical appointments and the possibility of an extended absence from school and extra-curricular activities. In these situations it is important for professionals and researchers to carefully consider their own opinions of cosmetic surgeries as well as their own interests in the academic success of the student and weigh them against the students own interest in the correction of their physical deformity. Professionals are called to provide guidance and support to the student and their family without imposing their personal opinions. Ideally, professionals in educational settings will be creative in continuing to provide educational services and support throughout any necessary absence on the part of the student, through home work assignments, readings, and other self-study options. Researchers will ascertain that their actions are in line with existing practices. [23]

The ethical principle of *Responsibility to Society* suggests that professionals and researchers alike have a responsibility to all members of society and are called to advocate for change when societal norms bring harm to individuals with physical deformity (CPA, 2001). The Guidelines for Non-Discriminatory Practice suggest that professionals can choose from any number of activities in order to best utilize their time and expertise in meeting this goal (CPA, 2001). For professionals and researchers working in educational settings, it seems appropriate to begin by focusing on their surroundings. Through the education of school staff and through programs aimed at reducing discrimination among students, professionals and researchers can contribute to societal change at the level of their own school communities. [24]

At a broader societal level, there have been a number of interventions designed to change stereotypes and negative behavioral reactions to physical differences. These interventions require an alteration of attitude and behavior on the part of the general public and, unfortunately, have been relatively unsuccessful, thus requiring further development and testing (THOMPSON & KENT, 2001). Professionals and researchers who are competent in working with youth with physical deformity are likely to have knowledge and expertise that would greatly contribute to the furthering of these programs, thus contributing to their responsibility to society. [25]

There are numerous ethical dilemmas that can arise within working relationships between educational professionals and researchers, on the one hand, and youth with physical deformity, on the other. Although these are only a few examples, they highlight the utility of the CPA Guidelines for Non-Discriminatory Practice for professionals in making ethical decisions. Although only Canadian psychologists are required to follow these guidelines, other professionals and researchers would likely benefit from this resource. [26]

5. Conclusion

There are a large number of physically deforming conditions that affect children and youth within Canadian schools. Physical deformity affects individuals in two broad ways, it influences the way they are perceived and treated by others and it affects their personal ability to function through an increased risk of social anxiety, embarrassment, depression, withdrawal, and low self-esteem (EINSIEDEL & CLAUSNER, 1999; SARIMSKI, 2001; THOMPSON & KENT, 2001). There is a great amount of variation in the way that individuals respond to their physically deforming condition. Research has shown that there are a number of factors that contribute to

these responses including the severity and visibility of the deformity, age, self-concept, values, competency, social skills, and most importantly social support (ANDERSON, 1982). [27]

Given the very serious affect of physical deformity on the lives of individuals it is important that professionals within Canadian schools have an understanding of those affects in order to provide on optimal learning environment for this special group of students. Despite their unique condition, students affected by physical deformity require equal access to educational services. Canadian psychologists have an excellent resource in the CPA Guidelines for Non-Discriminatory Practice, which outlines four, hierarchically ordered ethical principles (CPA, 2001). The four principles have been outlined as they relate specifically to work with youth affected by physical deformity. This has been followed by examples depicting the utility of this reference for practical application by educational professionals and researchers. The CPA Guidelines for Non-Discriminatory practice are an excellent resource for professionals working with individuals from a wide variety of backgrounds, including students living physical deformity. [28]

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