

LEARNING ACTIVITIES

Children of a Lesser God
Core Values in Therapeutic Recreation

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Abstract

Students in recreation programs are often introduced to laws that apply to therapeutic or community recreation services. Several of these laws have to do with policy regarding people who experience a disability. One important law is the Individuals with Disabilities Education Act (IDEA). In order for students to better understand the law and its implications, a learning activity is presented, designed to build upon previous instruction about language and attitudes. In this exercise, students learn to appreciate the struggle many parents go through as they seek an appropriate education for their child born with a disability. By playing the role of a parent, the students learn to use positive language in their descriptions of the child's needs and potential. At the same time, students demonstrate an understanding of the IDEA and find their "advocate's voice" when asking for appropriate services for their own child.

Keywords: *Disability, individuals with disabilities education act (IDEA), individual education plan (IEP), therapeutic recreation*

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Students planning a career in therapeutic recreation or community based recreation receive education about the power of language in terms of disability. Language is often used to identify and enforce boundaries of “other-ness” which creates an artificial distance between people. On the other hand, language can be empowering and can promote equality, dignity, and respect for people who experience a disability. Most students are introduced to the concept of “people-first language” in recreation classes and encouraged to adopt it as a basic formula for speaking about people with disabilities. This concept is presented in textbooks as an advocacy or grassroots campaign promoted by people who have experienced the negative, deleterious effects of language (Bullock, Mahon, & Killingsworth, 2010; Smith, Austin, Kennedy, Lee, & Hutchison, 2005). Becoming accustomed to speaking in this way, establishing personhood prior to one’s diagnosis or its traits, requires practice and effort, and is encouraged throughout the undergraduate curriculum. The following role-play activity allows students to integrate what they have learned about language into a dialogue about human value and potential through a discussion of educational policy. Afterward, the students are encouraged to build on that foundation as they become advocates for change.

Learning Methods

In a revision of Bloom’s taxonomy, Krathwohl (2002) states that remembering is a step toward understanding, but active learning should allow students to apply ideas and *create an original product* (such as a persuasive written assignment). Indeed, DeNeve and Heppner (1997) confirm that during a role play, students are “uniquely constructing knowledge for themselves” that prepares them for real world situations (p. 232). By using role play, the students are moving beyond remembering that language is important. They are applying the ideas and creating new language patterns for themselves. In addition to the awareness of language, it is also a powerful mechanism of attitude change because learners may alter their beliefs to correspond with the role assumed (Smith, Austin, Kennedy, Lee, & Hutchison, 2005). DeNeve and Heppner (1997) assert that this type of activity increases awareness of one’s own feelings and the feelings of others. These are valuable outcomes that warrant the use of an active learning style that finds its power in creating, constructing, while applying ideas presented in previous lectures.

Social Views on the Range of Human Diversity

A major goal of recreation education is to find value in people with different abilities who are labeled by society to be worth less than other people (Robertson, 2008). At various times in history, and in different countries, the socially acceptable options to deal with what were termed birth defects have ranged from institutionalization to sanctioned sterilization to euthanasia killings inspired by proponents of eugenics. Modern technological advances make it easier to identify and label disabilities based on biological indicators, thus focusing the dialogue on correcting supposed deficiencies or preventing them altogether. Disability advocates operate from a paradigm that sees such characteristics as within the normal range of human expression, and they fully support the idea that every person has the right to be in the world and contribute to it. Such individuals are not lesser beings formed by a “lesser god,” in reference to Tennyson’s poem “Idylls of the King” (Tennyson, Poetry Foundation, 2013).

This negative appraisal of human potential was taken to the extreme by the eugenics movement. In the 1930s, people with developmental delay and other disabilities were regarded as human “weeds,” and for the purity of the gene pool, anyone with lesser intellectual capacity was to be eliminated from it, through detection, prevention, and sterilization (Bullock, Mahon & Killingsworth, 2010). These attitudes were present in many countries, but in Nazi Germany there were babies who were actually killed after birth because they were deemed “life unworthy of life” (Binding & Hoche, 1920).

In 2006, the American College of Obstetricians and Gynecologists began recommending that all pregnant women, regardless of age, get their fetuses tested for Down syndrome and other chromosomal abnormalities (Associated Press, 2006). In 2008, *Newsweek* reported that 90% of the women whose fetuses tested positive for these abnormalities chose to abort (Carmichael, 2008). In the same article, Carmichael cites research showing that doctors do not present any positive information about quality of life and as many as 23% of doctors admitted trying to influence the mother's decision, usually encouraging them to abort.

Even today, in some countries of the world, it is permissible to conduct a euthanasia-style killing of a baby after it is born, but rather than being based on genetic purity, it is now reduced to an economic issue with moral overtones (Giubilini & Minerva, 2012). In the past, euthanasia was deemed to be what was best for the individual patient, thought to "relieve suffering" and such. But medical ethicists are now arguing for a radical change of direction. To make this end-of-life decision more accurate and perhaps more palatable, the practice is now being called an "after-birth abortion." Proponents claim that life is not precious until the being becomes self-aware and can appreciate what life is. Only then is something taken away. Until that time, others have the privilege of making the decision based on what is best for the family, the parents, or the caretakers. The procedure is no longer a mercy killing for the good of the "sufferer," but an economic decision, based on the desires of the parents (even though the decision may be based on inaccurate or deliberately biased information). There are now legal implications for doctors who do not test or discover these genetic issues prior to birth. "Wrongful birth" lawsuits have been shown to have legal merit, resulting in awards for the parents who were not given the information (deemed to be negligence) which would have allowed them to choose abortion during the early months of gestation and must now raise a child for which they are financially or emotionally unprepared (Lohr, 2012; Katrandjian, 2012).

In this milieu of social opinion, students learn about laws in the United States that require local governments to provide a Free and Appropriate Public Education (FAPE) for all children. This right was guaranteed by Congress in 1975 and has been renewed and clarified by more recent legislation, such as the Individuals with Disabilities Education Act (IDEA). Central to the concept of appropriate education is the identification of what that means for each child. That individual assessment of skills, strengths, and talents results in the collaborative creation of an Individualized Education Program (IEP) that establishes the expectations, goals, and resources needed to educate that child. Such a team exercise is meant to ensure that a child is never treated as a diagnosis or lumped into a treatment based on stereotypes or labels. Once declared and agreed to by all parties, the IEP becomes a binding document. School districts then have the obligation to fulfill the IEP and provide this education, but not all districts believe that they have the staff levels or talent required to meet the expectations in the written plan.

For a variety of reasons, some parents of a child born with disabilities choose to take their child to a private school. It may be that student-teacher ratios are more favorable, or that the available resources are greater than those found in public schools. These benefits offered at private schools often result in high tuition costs. This was true in Utah, where the family of Carson Smith found that tuition soared to \$21,000 annually at the Carmen B. Pingree School for Children with Autism. The family fought a long political battle to allow the release of funds that would normally be allocated for their son's education (\$3,100–5,300) so they could defray the costs of the private school. The resulting legislation became known as the Carson Smith Scholarship Fund. Either with or without this tuition "voucher," as it came to be known, the costs of private schooling would be prohibitive for many people who have a child with a disability (Lynn, 2004).

Other families experiencing the same frustration with their child's education have asked what became of the concept of a free appropriate public education. That is when Mr. Freston of New York filed a suit requesting that the school district pay the entire tuition fee for his son who was diagnosed with learning disabilities to attend a private school (Caruso, 2007). He claimed that the district was bound by law to provide the education as described in the IEP, and if the district were incapable of meeting this specific plan, they would essentially have to contract another agency to do it, but bear the entire expense, thus maintaining the "free" part of an appropriate education. Freston said, "Children with special education needs have a right, without jumping through hoops, to attend schools capable of providing them with an education that accommodates their individual needs regardless of their family's financial means" (Caruso, 2007, ¶. 19). This test case in New York was appealed and eventually went to the United States Supreme Court. The verdict resulted in a 4-4 tie, with one abstention. This ruling allowed the decision by the lower court to be upheld, and that meant the school district was required to pay the private tuition for any student where the scope of service detailed in the IEP was beyond the ability of the school district to provide (Supreme Court splits, 2007).

Because these laws differ by state and district policy, students used this case history as a starting point to compare and contrast policies in their own region. It also allowed a side discussion on the implications for the school district. The financial costs were the first topic of discussion, but there were also implications about staffing levels and skill sets that had to improve in order to fulfill the expectations of the IEPs written by other members of that very school district. A short discussion on this topic was valuable, as it helped students see the problem from the perspective of an administrator rather than a parent.

Learning Activity

In this learning activity, students play the role of a parent of a child with a disability. To help them get in character as a parent, they are given a short editorial by Emily Rapp titled *Notes from a Dragon Mom*, which appeared in the *New York Times* (Rapp, 2011). The positive language in the face of difficulty provides a balance to the posturing about who is to blame for the supposed tragedy, and focuses on the beauty to be found in the moment. Once in character, they write a letter to a local school district to advocate for their child's education. Students may take different tactics. Some might challenge the school district to provide better service, some might ask for a voucher, and others might demand full tuition costs of a private school education. In the letter students are challenged to use appropriate language and make a passion-based appeal on behalf of their child that reflects hope, value, and positive growth. In this exercise, the students will also demonstrate knowledge of the facts regarding the IDEA and public education for children with disabilities.

Some students found themselves in a moral bind during this learning activity. Some thought it was a waste, from an economic standpoint, to spend large amounts of money on this population. Perhaps their thought process was to spend school funds on the kids with the greatest potential to impact the world, or "get the best return" on the dollars spent. In some cases, students hearkened to the past and stated that segregated education is not fair and does not work, thus decrying the idea of setting up schools just for kids with autism. Those students (now thinking as parents) fought against the idea of placing all the kids with disabilities in special schools designed only for them, even if an IEP could be implemented better. To them, the social cost was too high a price to pay. Others struggled with using positive language to describe a child with autism or see a positive future for a child with Down syndrome, cerebral palsy, or spina bifida. This allowed discussion on the ways society benefits from individual contributions, using examples such as Temple Grandin, a person

with autism, who earned a PhD and by “thinking in pictures” (the title of an HBO film) impacted all of the North American cattle industry. It also prompts discussion of unconditional love like that shared between professional snowboarder Kevin Pearce and his brother David who has Down syndrome. Such love and support was very valuable to Kevin as he recovered from a brain injury that he acquired in a snowboarding accident. Kevin is now giving support back to David as the two brothers frequently appear together to promote awareness of developmental disability (KP & DP Buddywalk, 2010).

Not all responses or class discussions have been built around negative concepts. Many students who have chosen recreation as their profession already have some exposure to developmental disabilities through family, friends, school, church, and volunteer opportunities. This exercise is allows such students an opportunity to talk about experiences from the past and adjust the actors and attitudes to fit the role play. Students have typically found a tone that defends their child from stereotypes and lowered expectations and emphasizes the unique talents and abilities that are to be found by those who look for them. They find the balance between parental passion and well informed advocate who knows the law. Unexpectedly, another frequent response has been a sympathetic parent who understands the plight of the school district and offers to help personally, and promises to rally community support to meet the challenges facing the district due to budget allocations.

Outcomes

Students engaging in this learning activity had opportunities to practice the conceptual framework of “people-first” language and demonstrate how language can give dignity and hope to individuals who experience disabilities. Many students have been exposed to jokes about children in “special ed” or students who “rode the short bus” to school. By speaking positively about such children, they will begin to dispel stereotypes about children with disabilities.

- Inappropriate language will be discontinued and the student will be aware of groups who advocate for removal of offensive words such as retard, cripple, and phrases such as “confined to a wheelchair.”
- By learning about the educational process in our country and the laws regarding education for children with disabilities, students will be better qualified to act as professionals involved in childhood education, and they will be better advocates for families and individuals negotiating the complex education system.
- By practicing people-first language through this and other classroom activities, the student will be better prepared to engage with clients in any community setting where services are likely to be provided to people with disabilities.
- Students will view education and other social programs as a civil right and recognize that the people with disabilities are often denied rights and opportunities based on a discounted “other” status.
- Future recreation professionals employed in school, healthcare, or community recreation settings will see potential for growth and improvement based on individual strengths and weaknesses rather than stereotypes.

By actively looking for talents and skills that may be developed in a child, they may open up possibilities for a young person with autism to achieve a Ph.D. (Grandin, 1995), or a child with Down syndrome to become an actor in movies and television shows (Burke, 1991). As Negley and Bell (2010) stated, “recreation and therapeutic recreation services are necessary and critical in the process of change to improve the long-term quality of life for people with disabilities.”

Recommendations

The principle of practicing people-first language can be applied to anyone. Since some students may only be familiar with a verbal role-play scenario, they may be given opportunity to dialogue with others in the classroom prior to being given a written assignment.

Local laws regarding education for children with disabilities may have some variance, but they all must comply with the federal IDEA legislation. It may be very helpful for class members to hear from a family impacted by the law to illustrate local application of this federal mandate. This could be done through adaptations or variations from this exercise and might include a classroom roundtable that featured a parent, a school district representative, and a CTRS who has been involved in implementing an IEP. Similarly, students could also be assigned to interview the parent of a child who has an IEP in place. Lastly, a representative of the state government could be involved to educate students on the status of laws pertaining to a tuition voucher, a scholarship, or tuition payments to private schools that are available in a particular state.

Recommended Readings

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