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Intellectual Disability Discrimination

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Abstract

A lack of understanding concerning individuals with intellectual disabilities has led to exaggerated fears and diminished expectations. Consequently, these individuals have faced social exclusion. Research reveals, however, that societal discrimination can be stunted when people are given both information about and contact with these individuals. This research provides the foundation for a film documentary that provides society with the information and contact required to cultivate positive, inclusive attitudes towards individuals with intellectual disabilities.

Key words: *intellectual disabilities, individual education plans, Down syndrome, autism, prenatal testing, prenatal screening, documentary, mentally disadvantaged, individuals with intellectual disabilities*

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Intellectual Disability Discrimination

Kirsti Mutz

Introduction

Individuals with intellectual disabilities are largely viewed as liabilities to be managed rather than assets to be enjoyed. Because people have a false perception of the limitations and abilities of individuals with intellectual disabilities, they remain regularly undermined and discriminated against. A lack of understanding concerning this population has led to exaggerated fears, and diminished expectations. Research suggests, however, that providing information alongside personal contact can change previously negative attitudes into positive outlooks (ten Klooster et al.; Anthony). Consequently, a society will be cultivated that engages, rather than avoids, the mentally disadvantaged.

Research Questions:

1. How are individuals with intellectual disabilities (IID) being discriminated against?
2. What are effective advocacy methods? What is the most effective method to implement in ending intellectual disability discrimination (IDD)?
3. How can every individual be empowered to make a change in IDD?
4. What is the best method to educate society concerning IID? What is an accurate, unexaggerated view of the lifestyle of an IID?
5. How do we build a community of inclusion for the intellectually disabled?

Review of Literature

The Problem

Discrimination occurs when a person or group of people are unjustly treated and prejudicially placed into a separate category. Intellectual disabilities range in severity and kind. However, regardless of type, the general stigma towards intellectual disability is overwhelmingly negative, both on a local and global level (Littlewood). While the undermining of this specific population occurs in the workforce, and legislative work is a necessary component in protecting the rights of IID, the focus of this research is to examine the lack of value shown towards the disabled population on a more micro, individual basis. While this review recognizes the IDD issue on a macro level, it concentrates on how to successfully address the discrimination issue on a more interpersonal basis.

One drastic example of IDD pertains to the termination rate of Down syndrome fetuses in comparison to those that develop typically. Pre-natal testing allows for women to gather information that either confirms, or denies the presence of potential congenital abnormalities in the fetus. One of the primary things these tests look for is the likelihood of the fetus being born with Down syndrome, one of many intellectual disability disorders. When pregnant women receive results that confirm the presence of Down syndrome, 86.9% choose termination, while only 13.1% continue with their pregnancy (Kramer). Pregnancies with typical development, however, do not see this kind of termination rate post pre-natal testing.

Numerous studies have been conducted to discover the reasoning behind women's decisions and attitudes regarding this situation (Park and Mathews; Pruksanusak et al.; Kitsiou-Tzeli et al.; Yanikkerem et al.; Sahin and Gungor). While different research

highlights different aspects, it thematically concludes that women do not have enough information when it comes to pre-natal screening tests (Kitsiou-Tzeli et al.; Yanikkerem et al.; Sahin and Gungor). Without accurate amounts of information, people are unable to respond fairly. Consequently, many potential IID are being terminated. This aspect of discrimination could decrease if more information were to be provided to potential mothers concerning their test results.

Although pregnant women possess a basic level of knowledge regarding these procedures, more information needs to be made available to them. Numerous studies have assessed the amount of knowledge potential parents have concerning pre-natal screening at different social, and economic levels. Whether at a high or low level in either of these aspects, studies identify the serious need for an increase in pre-natal counseling, especially for immigrants and those with a low level of education (Kitsiou-Tzeli et al.). Another study confirms the need for a greater provision of counseling for those who are under-employed, under-educated, and under the average economic standard. Members of this population were significantly less knowledgeable about understanding prenatal screening for Down syndrome. Additionally, researchers discovered that most of those women would ultimately choose to leave the final decision up to their health care providers (Yanikkerem et al.).

Studies show that woman primarily educate themselves about prenatal testing through friends and family, rather than through more objective sources. Both Park Pruksanusak conclude that pre-natal care providers should begin discussing the possibilities of testing earlier in the pre-natal process in order to provide potential mothers with an ample amount of time to gather information and opinions concerning these tests

(Park and Mathews; Pruksanusak et al.). Anxiety regarding pre-natal screening exists in multiple areas, as the risks and information it entails is too important for there to be a lack of understanding (Sahin and Gungor). One way to dampen IDD is to proactively push for healthcare providers to deliver more information at each step of the process, so that women are receiving information from more balanced, factual sources.

While IDD exists on a global level, it is also extremely evident on an interpersonal basis. Attitudes inform actions, and by reforming the individual's attitude, the global attitude will subsequently be reformed. Currently, the overarching attitude toward IID is holistically negative. According to Devlieger, the relationship between the ways disabled persons are viewed is directly correlated with the expectations society has for them (Devlieger). There have been various attempts to correct this negative feeling towards intellectual disabilities. Research conducted by William Anthony synthesizes information from various studies concerning what method is best in changing society's attitudes towards individuals with intellectual disabilities. Anthony compares three types of studies: one where the participant has only contact with a mentally disabled person, one where the participant has only information about a mentally disabled person, and one where the participant has both contact and information with a person with mental disability. Anthony concludes that little to no change of attitude occurred in the first two scenarios, but an increase in positive attitudes consistently resulted when both contact, and information was provided. Individuals who receive only information about a disability are detached from an emotional investment into the life of an IID. Conversely, people who have only contact without information do not have a full understanding of an individual with an intellectual disability. If the intellectually disabled are to be valued, rather than

undermined, both information and contact must be provided to society. Through the pairing and provision of these two aspects, attitudes will begin to shift and Intellectual Disability Discrimination will begin to diminish.

The Solution

Removing Fear

A lack of information concerning the ID population has led to exaggerated fears, and diminished expectations. Both need to be addressed to properly advocate for better treatment towards IID.

Fear stems from a lack of understanding. Providing accurate information on what life with an intellectual disability looks like, as opposed to what society has assumed it to be, will relieve these exaggerated fears. As stated above, a greater amount of information needs to be provided concerning pre-natal screenings. Beyond that, however, two significant issues need to be addressed: the quality of life for an IID and the quality of life of those parenting an IID.

One of the central pre-suppositions about intellectual disabilities is that an IID has a poor quality of life. This mindset, however, is based more on assumptive opinions than justified facts. According to Samson and Antonelli IID, specifically autism, have different values than those who develop typically (Samson and Antonelli). They discovered that autistic individuals did not differ from typically developing individuals in regard to their satisfaction with life (Samson and Antonelli). Research suggests that the quality of life characteristics valued by individuals without disabilities are not the same characteristics valued by persons with intellectual disabilities. Although the characteristics valued by both

groups are different, both people with intellectual disabilities and those who are developing in a typical manner claim to be satisfied with their lives. It is important to emphasize that difference does not constitute inferiority. Just because something is different does not make it wrong. To assume that IID have a poor quality of life is erroneous, and without substantive evidence.

Physicians play an influential role in the diminishing intellectual disability discrimination through educating about these conditions. One review from the National Center for Learning Disabilities summarizes the ways in which doctors can help I (Horowitz). These strategies include: dispelling falsehood, teaching the differences between disabilities, and empowering individuals to become their own advocates. Horowitz is hopeful that educating individuals will enable members of society to stop looking for the inexistent “cure” for intellectual disabilities, and rather, begin building the most effective strategies for their success. The solution is not say there are no difficulties, but to educate individuals accurately concerning those difficulties, and how to successfully in spite of them.

Another important issue to address is the quality of life and level of parental satisfaction of those individuals parenting an IID. While parenting a child with an intellectual disability differs from parenting a child who develops in a typical manner, both scenarios involve complications and achievements. As parents anticipate having a child, they generally focus on the excitement that accompanies such an event and anticipate the joys of raising a family. However, when parents anticipate having a child with an intellectual disability, they focus on the difficulties: medical complications, educational difficulties, and financial strains. Yet, both scenarios include excitement and difficulties.

Even typical pregnancies could involve medical complications, educational difficulties, and financial strains. Conversely, pregnancies of children with an intellectual disability should still anticipate the joys of raising a family. To begin diminishing Intellectual Disability Discrimination in regards to pre-natal testing, parents must begin realizing IID are no different from children who develop typically, in the way that both contribute difficulties and benefits to society.

The majority of women claim they are too ill equipped to raise a child with an ID, and therefore terminate ID pregnancies (Gilmore and Cuskelly). However, research shows women who previously distrusted their ability to raise a child with an ID ended up finding themselves capable to do so. Gilmore and Cuskelly conducted a study of 25 mothers in an attempt to compare the typical parent's sense of competence with that of a Down syndrome (DS) parent's sense of competence and satisfaction. The authors found that the amount of satisfaction and self-efficacy felt by parents of DS children compared similarly to that of parents with typically developing children. Though most people fear parenting a child with an ID, this study recognized that parenting a child with an ID does not impact the amount of happiness or self-efficacy felt by mothers. Conversely, DS mothers grew in their satisfaction by 2.2 points, while typical mothers only increased in satisfaction by 0.42 points during the childhood to adolescent phase. While parenting a child with an ID has difficulties, mothers do not seem to suffer in contentment or satisfaction when raising a child with this disability.

Raising Expectations

A lack of information about the strengths of those with ID has created an uneven focus on the negative aspects associated with ID. Consequently, society has cultivated a lack of expectation towards IID. However, exploring the strengths of IID, this sub-culture can be enjoyed rather than tolerated. Making generalizations about individuals with ID results in them being treated with low tolerance. Yet, research shows that educational and vocational success is achievable for those with ID when their strengths are properly understood and plans of individualization are created (Capo). Capo hypothesizes that advances could be made in the education and development of these individuals if a proper understanding of their abilities were comprehended.

Cognitive and linguistic abilities of those with ID are not being addressed appropriately. Such findings emphasize the need for individualization in education plans for IDD (Wishart). Research reveals the success that can be obtained through capitalizing on the strengths of these individuals, rather than focusing on their weaknesses (Bellini and McConnell). Currently, the strengths that individuals with ID have to offer (i.e. scientific-interests, positivity, etc.) have remained underrated. However, when their needs are met, those specific strengths can be seen and utilized (Motttron).

Educating and integrating IID presents a challenge due to the fact that their struggles are different. However, research suggests that helping them achieve self-efficacy is possible when the effort is put forth. Problems such as lack of basic, personal health care, or abuse have been remedied through solutions as simplistic as continual prompting (Herron-Foster). Educational goals have been realized through solutions as simple as creating specified plans (Tincani). Providing more information to society will enable them

to create more individualized plans and empower those with ID to achieve educational and vocational success.

While self-advocacy can solve a plethora of problems, students with ID rarely acquire the skills needed to campaign for themselves. One of the most influential ways the intellectually disabled have been empowered is via self-advocacy training. In order for IID students to receive the best future possible, they must have a proper understanding of themselves (self-awareness), and apply that understanding (self-realization). To accomplish this, surveys have been created for educators and students that provide an accurate view of what is needed to ensure the success of each student's future (Schreiner). Further studies confirm that self-determination and advocacy training is irreplaceably influential (Clark et al.).

In order to address the need for self-advocacy education, researchers have developed and implemented multiple strategies. One strategy provides the disabled with greater rights by encouraging advocates and social workers to take the time necessary to listen to them (Knight and Oliver). However, such a strategy would present a challenge for those individuals with poor communication skills. Another suggested approach has been to protect the rights of the children by advocating for good legislation and then keeping to it strictly. However, this is also problematic because legislation does not provide for the specific needs of each individual child. Research concludes that while determining effective strategies for self-advocacy can be difficult, it is feasible when a proper amount of time is invested into each individual child (Knight and Oliver; Mulick and Butter).

People are willing to make positive changes when they feel equipped and empowered. Research suggests the primary agent for effective advocacy is creating and

maintaining good community where families of IID receive encouragement and celebrate advocacy successes (Hess et al.).

The key to effective self-advocacy is individualization, and the key to effective individualization is the provision of accurate information. Consequently, counteracting the negative stigma against IID will occur through raising society's expectations for what the IID can offer, and that will only be accomplished through providing more information than is currently made available.

Methodology

To cultivate a society that engages, rather than avoids, the mentally disadvantaged, this documentary will implement a two-part method. While providing information is the first step to diminishing fears and raising expectations in the attitudes towards those with intellectual disabilities, research suggests that lasting attitude change also requires personal contact (ten Klooster et al.; Anthony). Information without contact lacks empathy. Contact without information lacks understanding. Individuals who receive only information about a disability are detached from an emotional investment into the life of an IID. Conversely, people who have only contact without information do not have a full understanding of an individual with an intellectual disability. If IID are to be valued, rather than undermined, both information and contact must be provided to society.

This documentary will build positive attitudes towards the intellectually disabled through providing information about different conditions that affect an individual's intellect through interviewing various health professionals. Additionally, it will provide

contact through following the lives of five different individuals with various intellectual disabilities.

The film will follow the involvement of each individual in Lakeland Community Theater's *Out of the Box: A Troupe with Unique Abilities*, a program that provides intellectually disabled individuals with the opportunity to do live theater. While documenting the process from practice to performance, it will explore more deeply into the struggles, families, education, and achievements of each individual. Doing so provides viewers with the contact required to build positive attitudes towards the intellectual disabled. Though this may not offer the opportunity for physical contact to the viewers, it provides them with vicarious contact, which has similar effects of building empathy and affinity. Consequently, the viewer's attitudes will begin to positively change towards IID that they eventually will encounter throughout the remainder of their lives. Additional footage interviewing health professionals will be included to provide the viewer with information, research, and understanding.

Through the inclusion of information and contact, viewers will be provided with the needed aspects that cultivate positive attitudes toward IID. Subsequently, intellectual disability discrimination will decrease as fear is removed and expectations are raised.

Conclusion

Greater amounts of people need physical contact with individuals with intellectual disabilities. However, typical individuals still need to learn without the distractions of students with special needs. Contrastingly, students with special needs need more

individualize attention than those who function typically. To expand upon this research, one could begin asking how to increase socialization between typical individuals and individuals with intellectual disabilities while still catering to the needs of each group.

The implications of this research can be vastly expanded upon. Providing people with contact and information in order to cultivate less discriminatory attitudes is a simplistic idea that can be implemented by every individual. Generally, the audience for these ideals is readily receptive and does not need to be convinced there is a discrimination issue towards individuals with intellectual disabilities. However, few people are moving proactively beyond understanding the issue and acting on these principles. In order for these conclusions to have substantial impact, individuals must actively begin implanting these concepts in their daily lives.

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