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Self-injury and Behavior Supports for People with Intellectual Disability

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Individuals with intellectual disabilities (ID) have been supported with the philosophy that they should have freedom and control in their own lives. Since the 1960s, there have been many advocacies for individuals with intellectual disabilities. *Christmas in Purgatory* (Blatt & Kaplan, 1966), with text written by Burton Blatt, revealed the dirty and filthy environment where children were locked in cells and the inhumane treatment people with disabilities were receiving thus humane treatment and freedom for these people were advocated. With President Kennedy's administration, together with many advocates and other parties, people with ID obtained numerous opportunities to enjoy their lives. Special Olympics, a big stride in the history of intellectual disability, has been supporting people with ID by accepting them as athletes so far. Needless to say, much has been learned on the causes and treatments of ID, which has provided valuable insight to support individuals with ID in changing their lives in the past several decades.

Nevertheless, we are still on the way to applying more comprehensive methods to support the needs of persons with ID. Self-injurious behavior (SIB) is one of critical concerns of professionals. People who exhibit SIB hurt themselves and others. There are many forms of SIB and serious consequences of it. Fish (2000) mentioned that strong emotions can be elicited in people with ID. It is difficult but nevertheless critical to address this challenging behavior.

The purpose of this paper is to seek strategies that can be effective to support behaviors of individuals with ID. The major topics will be addressed include the characteristics of people with ID, concerns and causes of SIB, and interventions used

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to address this behavior. The paper then concludes with a discussion of choosing different strategies for individuals with ID to accommodate individuals' needs.

Intellectual Disability and Self-injurious Behaviors

The American Association on Intellectual and Developmental Disabilities (AAIDD) defined that intellectual disability is “characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills and this disability originates before 18” (AAIDD, 2010, p.1). Generally, they have an IQ score that is about two standard deviations below the average. They may have adaptive behavior deficits in conceptual skills, social skills and practical skills.

Luper and Lockley (2008) noted that people with ID display maladaptive behaviors that include self-injurious behavior (SIB), aggression, and noncompliance. Increasing attention has been given to SIB as it is least likely to be changed once this behavior presents (Maclean & Dornbush, 2012).

Brown and Beail (2009) identified three types of self-harmful behaviors. The first type of self-harmful behavior focuses on behaviors that cause extreme injury and the third type deals with behaviors that associated with psychologically disturbed problems. The second type is what we are discussing here, termed as self-injurious behavior that involves people with ID.

According to Ristic (2005), Tate and Baroff (1966) defined SIB as behaviors that cause injury to the individual's own body, with demonstrable tissue damage such as

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swelling, bruising, bleeding, or broken bones. Attention has also been paid to the forms of behaviors. Currently SIB is used to describe both the form and its consequences (Maclean & Dornbush, 2012). MacLean and Dornbush (2012) indicated that the most common topographies include head banging, hitting, and self-biting.

According to Kahng, Iwata and Lewin (2002), the prevalence was 7-23% in ID populations. It was much higher in people with significant disabilities, with 71.2% of reported cases. It is unknown if it is a result of institutionalization since people with severe intellectual disabilities in the past were most likely to be placed in institutions. Based on Kahng et al., hitting or head banging and biting are most common self-injurious behaviors. Hitting accounted for 49% of self-injurious behaviors and biting accounted for 30%. Ristic (2005) noted that there are common characteristics of SIB among people with ID, such as repetitive movements and the same movement displayed many times of a day.

Causes of Self-injurious behaviors

The causes of self-injurious behaviors vary from genetics and biochemistry to psychological issues, which have been researched most in the causes of maladaptive behaviors of people with ID. Sensory processing that needs to be researched on its influence on self-injurious behaviors can be an important factor too.

Genetic causes are important in cases of intellectual disabilities. Genetic processes include dominant transmission, recessive transmission and sex-linked inheritance. Sex-linked inheritance includes sex-linked dominant inheritance and sex-linked recessive inheritance. For sex-linked recessive inheritance, the

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pathogenic gene is on sex chromosomes, always on X chromosomes. As the male has only one X chromosome, one pathogenic recessive gene will cause the male to be affected. Lesch-Nyhan and Fragile X syndromes are two typical examples of X-linked recessive disorders. Self-injury is a distinctive problematic behavior in individuals with Lesch-Nyhan. The forms involve biting and hitting. Fragile X syndrome is an ID caused by genetic conditions. They also characterized as exhibiting self-injurious behaviors (Genetics Home Reference, 2013). Polloway, Smith and Antoine (2008) noted that children with Lesch-Nyhan display extreme self-injurious behavior, as they have an uncontrollable urge to cause injury to oneself. Polloway et al. (2008) also indicated a report that severe behavior problems such as self-injury were observed in individuals with fragile X syndrome.

Biochemical factors cannot be ignored. Long term exposure to lead can cause developmental disability. There are a variety of studies that had been done and proved the association between self-injurious behaviors and chemical matters in our body. Edelson (2004) noted that self-injury is associated with chemical matters like serotonin and dopamine. According to Edelson (2004), in a study on a heterogeneous population of individuals with ID, Greenberg and Coleman (1976) reported that self-aggressive behaviors increased after reducing the level of serotonin by drugs. Coleman (1994, cited by Edelson 2004), discovered that individuals who had low calcium levels often exhibited eye-poking behavior, and calcium supplements help improve the behavior significantly. Edelson (2004) further noted another finding

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reported by Muller and Nyhan (1982) that drugs which elevate the level of dopamine can initiate self-injurious behavior.

Brown and Beail (2009) reported on their qualitative research study of self-injury among people with ID. Nine participants who harmed themselves were interviewed. Brown and Beail (2009) found that “self-harm was seen in the context of coping with powerlessness and abuse, controlling emotional distress and blame” (p. 504). Because of the small sample size and single case nature of this study, more replication research needs to support the findings. In this research, reasons for self-injuring include past relationships like abuse and loss of families, the disturbing environment and the protective nature that they hurt themselves to avoid hurting others. For the whole self-injuring period, the participants felt angry before self-harm. They did not feel pain while harming themselves. However they would feel guilt after harming themselves (Brown & Beail, 2009). It is interesting to note that the participants would like to manage self-injury.

Besides what people have researched most, other factors such as sensory processing can be a reason why people engage in self-injurious behaviors. Joosten and Bundy (2010) noted that persons with developmental disabilities are more likely to engage in repetitive behaviors, and the reason for it is they are so sensitive that they want to reduce the anxiety and to avoid the sensation.

Interventions

Based on different causes of self-injurious behaviors, a series of interventions have been designed. Heyvaert, Maes and Onghena (2010) did a

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meta-analysis through searching and analyzing literature in the databases to see the intervention effects on behaviors of persons with ID. The research concluded that the three types of interventions, namely, biological intervention, psychotherapeutic intervention and contextual intervention, are effective in reducing problematic behaviors among people with ID. Heyvaert, Maes, Noortgate, Kuppens, and Onghena (2012) did a similar study and confirmed the significant effect of contextual, behavioral, and pharmacological interventions.

Edelson (2004) noted that the individual's biochemistry can be balanced through nutrition and medication. In turn, the self-injurious behaviors can be reduced. Vitamin B6, calcium and restricted diet can eliminate self-injurious behaviors. Except medical intervention, there are many other ways to inhibit self-injurious behaviors.

Luper and Lockley (2008) stated that self-injurious behaviors can be caused by learned helplessness, which is often reinforced carelessly by others. Brown and Beail (2009) described in their action research that expectations and rules were taught to 36 females with ID, who exhibited self-injurious behaviors. Along with it, positive reinforcement was used. For example, they were allowed to go for a field trip if they have cumulative good behaviors. Before the intervention, these ladies with ID thought they should be rewarded even at the simplest thing they did correctly. After teaching them rules, these people behaved more appropriately and not in a state of learned helplessness.

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Functional behavioral assessment is based on behaviorism. Skinner (1969) said the reason why people behave in certain ways can be found in the consequences of that behavior as the behavior that interact with the environment produces consequences, which we call reinforcers. Functional behavioral assessment can be conducted to identify the reinforcers, to see what maintains the problematic behaviors and identify the contingencies. According to Skinner (1969), “man is an animal and share many basic behavioral processes with other species. It has been possible to study complex behaviors that once attributed to higher mental process.” (p. 94). The alternative behavior can be replaced through reinforcement by delivering the reinforcers contingent on the desired behavior.

Functional assessment has been a major tool in treating SIB. Functional assessments are used to identify the function of the behavior. Prior to the assessment, an operational definition of the self-injurious behavior which should be specific and measurable is developed. Direct strategies like anecdotal records and ABC analysis chart and indirect strategies like informant interview are used to obtain environmental stimulus around the behavior, including the antecedent, the topography of the behavior and consequences. Sometimes there are more than one functions for one specific behavior. For example, Edelson (2004) noted that a person engaging in wrist biting might be due to his or her incapability of communication or because of not getting something he wants.

Rojahn, Zaja, Turygin, Moore, and van Ingen (2012) compared the functions of three types of behaviors among persons with ID and suggested that while external

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contingencies maintain aggressive behaviors, SIB is more likely to be maintained by non-social (automatic reinforcement) contingencies as the topographies of SIB is repetitive. Ristic (2005) discussed that SIB are reinforced by tangible, attention, sensory stimulation and demanding, liking avoiding going to school.

After knowing the functions of behavior, interventions can be designed. As Edelson (2004) suggested, if the function of self-injurious behavior is to obtain attention, the caretaker must ignore the behavior and avoid any facial expression. If the self-injury displayed is because of obtaining some tangible, caretakers can teach the person how to make request to get it. Communicating skills are necessary to be taught in this situation. Sometimes self-injury occurs because of failure to communicate with caretakers. According to Alberto and Troutman (2013), in an escaping situation, the person may self-injure when somebody approaches him/her or the person is given a hard task to do, the caretaker may either reinforce the person by making a verbal request for doing something else or remove the antecedent stimulus. Considering the severity of the behavior, differential reinforcement of other behaviors (DRO) can be adopted. Alberto and Troutman (2013) suggested that a session can be divided into small intervals so as to provide the person more opportunities to engage in the desired behavior and be reinforced. Once the person can control his or her behavior, the professional may increase the intervals. SIB therefore can be gradually eliminated.

Heyvaert et al (2012) concluded that manipulating antecedent factors will be more effective in other interventions that do not use it as a component. Heyvaet et

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al. (2012) noted that “the antecedent factors can be environmental, instructional, psychological and social. Interventions such as reducing task difficulty and making daily schedule more predicable can greatly decrease problematic behavior.” (p. 778).

Ristic (2005) also pointed that rearranging the natural environment is a promising treatment, including avoiding exposure to stimulations and teaching established expectations and rules in advance.

Edelson (2004) mentioned that if the self-injurious behavior is so severe that it causes serious consequences and other strategies failed to inhibit it, then aversives can be considered. Edelson (2004) also noted that visual screening strategy has been shown effective in eliminating self-injurious behaviors.

Discussion

This paper discussed the characteristics of people with intellectual disability, and the self-injurious behaviors they exhibited. Causes of self-injurious behaviors combined with etiology of intellectual disability are elaborated on as a basis for suggesting related interventions. Functional behavioral assessment and reinforcement are addressed. Related principles and rationales are analyzed.

Continuous efforts have been made to help persons with ID live a richer life as others. SIB remains a critical concern. Professionals should be careful in choosing a strategy. As there are many factors that may cause SIB, it is not easy to determine a single strategy. Comprehensive treatments should be encouraged in incorporating genetic, biochemical, and social psychological factors.

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Ristic (2005) noted that since SIB is complex, they should not be solely managed by individual incident. Screening should be conducted before functional behavioral assessment as medication may be used to terminate the self-injurious behavior. As mentioned, a variety of interventions, including medication, explicitly teaching expectations and rules to help individuals with ID get out of learned helplessness, positive reinforcement, antecedent control communicating training, and aversive stimuli can be conducted based on individual characteristics.

As SIB can be dangerous, it is recommended that the treatment be conducted by qualified professional and involve guardians or human rights committee. Meanwhile, the progress should be monitored and the treatment be evaluated regularly (Ristic, 2005).

There are still questions left for considering. How can the treatments be combined to effectively eliminate SIB? How does ID influence SIB and the forms of SIB? And which strategy, biochemical or contextual interventions plays a more effective role in eliminating self-injurious behaviors? With these questions addressed, we may have a deeper and more comprehensive understanding of self-injurious behaviors and more effective interventions can be adopted.

Some may think of people with ID as a “simpleton” or “fool”. Some may even think they are dangerous because of their abnormal behaviors. However, others may think of the lovely images like brave Forrest Gump who is loyal to his friends or Carla Tate who is determined to be independent. They are all people who have needs but, with support, can make a difference in their lives and our lives, just like

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Larry Selman, the Collector of Bedford Street, who lived a meaningful life with the support of his neighborhood. With a better understanding of intellectual disability, for example, with a good knowledge of self-injurious behaviors exhibited by people with ID, we may support their behaviors with effective strategies and therefore better include people with ID into our community.

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