

Kingsley S. Ceña

Ms. Jasmin Ibanez

12 November 2015

### **Only Way is Up for Down Syndrome**

The article “What is Down Syndrome?” states that Down syndrome (DS) occurs to an individual when s/he possesses a duplicate of chromosome 21, as whereas humans should only have one copy of chromosome 21. Due to this abnormality in the human anatomy, the cells of this individual experience difficulty in controlling how much protein is made and may lead to malfunctions within the body, as reported in the article “What is Down Syndrome?”

It has often been reported that due to these malfunctions within the body, children diagnosed with DS usually experience delays in their development and have problems with behavior. The article “Down Syndrome” explains that the delays in their development include slower development in speech and language, which makes their verbal activities harder to understand and “attention problems, obsessive/ compulsive behavior, and stubbornness or tantrums. These delays consequently prevent the individual from fully functioning as an adolescent, also stated in “Down Syndrome.”

Just as any normal person, an individual diagnosed with Down syndrome becomes a well-functioning adult if he or she lives a balanced leisure lifestyle, as stated by Roy Brown. Coyne and Fullerton described a balanced leisure lifestyle as a lifestyle that includes the individual fully immersing and successfully engaging himself or herself in activities (Tincani and Bondy 210). These activities must be such that will provide meaningful and appropriate recreation to the individual’s life in order to heighten quality of life which includes, “enjoyment, leisure satisfaction, well-being, relationships, and participation in the home and community” (Tincani and Bondy 210). Brown also stated that it is important for an individual with DS to be in an environment that promotes a proper living arrangement,

balanced lifestyle, involvement in the community, and employment. Moreover, Brown stated that if this environment has been properly integrated with all the concepts and ideas of a well-balanced lifestyle, then a DS patient will have a higher chance of being a well-rounded adolescent and thus, will lean to live independently later on. Furthermore, Genevieve Caballa, executive director of a special education school based in the Philippines, stated that, “[a]n inclusive society would enable a person with DS to develop his/her potentials to the fullest.”

Some notable programs have been made to incorporate this type of lifestyle in patients with DS specifically regarding proper living arrangement, employment, and appropriate activities that may heighten quality of life. All aforementioned aspects were mentioned by authors Roy Brown and Coyne & Fullerton as environmental factors that may lead the individual to become a well-rounded adult despite the presence of the syndrome.

## **Housing**

Patients diagnosed with DS, along with their families, consider transitions in living arrangement as a vital part of entering adulthood and a step closer for the patient to independent living, as stated by the National Down Syndrome Society (NDSS) in their article “Life after High School”. However, it is inevitable for the parents of the patient to worry about the safety of their child and would not be comfortable with leaving them on their own.

To address this problem, Marbridge, a campus based in Texas, U.S.A, offers an alternative living arrangement for DS patients which is called *assisted living*. According to their site *Marbridge.org*, not only does assisted living entail the patient to a residential care program that is fully dedicated to their basic necessities 24/7 but it consists of an environment well-suited for the patients, primarily caused by the fact that they only cater to residents that are diagnosed with the syndrome as well. Also, assisted living also consists of what Marbridge calls *Life Skills training*, a program that aims to educate the patients in different activities vital in independent living, as stated in *Marbridge.org*. The skills taught by

*Life Skills* ranges from shopping, cooking, money management, and other skills that may help the individual achieve the ,”highest level of personal independence possible.”

It was also stated in “Life After High School” that it is necessary to evaluate if the living arrangement of the patient ensures “good health, independence, privacy and dignity while ensuring safety.” The New York-based organization also stated that it is also vital for the patient’s needs to be met –“medical, physical, social, emotional and personal safety.” These are the exact needs PathfinderVillage aims to meet. PathfinderVillage, now a 300-acre non-profit organization in New York, started as a small school in 1922 that aimed to raise awareness for patients diagnosed with DS and also offer tailored education for them, as stated in their website *Pathfindervillage.org*. Now, PathfinderVillage not only offers attractive apartments that is monitored 24/7 by their security, but it also boasts Senior Residential Coaches (SRC). SRCs are the ones in charge of handling the daily activities of the residents, assisting every resident with their necessities. All in all, with one SRC assigned to each home, “[r]esidents benefit from life skill instruction, nutrition and meal planning, personal wellness and community awareness.”

## **Employment**

The article “Employment Issues for People with Disabilities” states that most adolescents that are facing delays intellectually are unemployed despite the fact that they are capable and willing to work in their respective communities. The article also cited reports published by the United States Bureau of Labor Statistics (BLS) indicating that intellectually disabled people report many hurdles in attaining proper employment. The most notably dominant hurdle reported is discrimination, as stated in the article “Employment Issues for People with Disabilities.”

Down Syndrome Victoria (DSV), an Australian-based support organization for Down syndrome patients, provides programs that may protect these individuals from further societal discrimination but still encourage employment. Futures for Young Adults is an

example of said programs. In an article in their website entitled “Transition to Employment”, DSV describes this program as their mean of providing support for DS patients in their transition to career-related paths. Transition to Employment or TTE programs the mindset of the individuals in order to prepare them for the field of employment through goal-planning and development of “work readiness skills.” Furthermore, TTE also provides assistance to the patients in attaining on the job training in different establishments and “participation in work placements.”

WorkFit, a project of Down’s Syndrome Association, was designed in order to connect the patients to employers, as stated in the article in their site, *Downs-syndrome.org.uk* , "Down's Syndrome Association: WorkFit.". The program aims to inform employers more about the profiles of the patients and educate the patients what to expect in the world of employment. WorkFit’s own website, *Dsworkfit.org.uk*, provides employers a list of individuals with DS and their specific set of skills acquired through the years and for the individuals, full support and assistance in connecting to these employers. All in all, WorkFit “bridge[s] the gap between employers and employees with [DS],” stated in the article "Down's Syndrome Association: WorkFit."

### **Life Quality- Heightening Activities**

Roy Brown said that key events or activities in the individual’s life may “help to build a positive self-image and increase self-esteem,” if these activities more or less promote a positive environment.

One of the programs that promote this is Special Olympics, an organization dedicated to reach 200 million people with intellectual disabilities through sports. Their goal is to deliver to these individuals one message – they can still be successful despite their disabilities. This organization hopes to achieve this through providing different forms of trainings, competitions, health screenings, and fundraising events in different variety of sports. Through this, not only the patients become more determined and physically stronger,

but also ignite in themselves a stronger willpower which will, in time, encourage them to overcome barriers brought by their physical or mental disabilities.

Stay Up Late is another charity that dedicated itself to improving the quality of life of individuals with DS. According to Kathryn Bromwich, who wrote about the charity in *The Guardian*, the charity aims to provide a higher quality of life by helping the patients, believe it or not, stay up late attending music social events. It was stated in the article that the founders of the charity observed that people with the syndrome never get to fully enjoy social events 'till the late night since they're highly dependent on the schedule of their caretakers. So, to solve the problem, the founders set up Stay Up Late, which hires volunteers to accompany the patients to social events, mostly music gatherings.

## **Conclusion**

As stated previously, individuals diagnosed with DS often, if not always, develop cognitive delays, as mentioned in "Down Syndrome". And these delays hinder these individuals from being a well-rounded & independent adolescent, as mentioned also in "Down Syndrome". Cabella stated that the individuals should be "exposed to real-world experiences in order to integrate [themselves] to community living," and these programs may present the appropriate measures and means for the individuals to properly and appropriately "integrate themselves to community living" and hopefully, later on, fully achieve independence.

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