

Quality of Life for Individuals with Disabilities During the COVID-19 Pandemic

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Abstract

Individuals with disabilities go through many transitional periods throughout their lifetime, and each series of transitional decision(s) has a direct impact on one's quality of life. Educators and families want to see young adults experience a quality of life with opportunities to have independence, a job where they receive a paycheck, and a life where they can enhance their overall personal outcomes (Center for American Progress, 2019; Emerson et al., 1996). For some, quality of life may entail pursuing dreams, accomplishing goals, and living life to the fullest (American Association on Intellectual and Developmental Disabilities, 2015). Other individuals may be content with where they are at the present moment. Quality of life (QoL) for people with disabilities varies with each individual. It is different for each diverse family who has a young adult with a disability, especially when varying factors are beyond their control (World Health Organization, 2020). This manuscript will explore what quality of life is and what it means for individuals with disabilities during the COVID-19 Pandemic.

Keywords: Quality of life, COVID-19, Self-Determination, Choice-Making

Quality of Life for Individuals with Disabilities During the COVID-19 Pandemic Quality of Life for Individuals with Disabilities

Individuals with disabilities go through many changes throughout their lifetime. They transition from elementary to middle school, from middle school to high school, eventually most individuals with disabilities transition from high school to a post-secondary educational program. These young adults with disabilities often work in a competitive employment setting, work with a job coach, or in a sheltered workshop (American Association on Intellectual and Developmental Disabilities, 2015). These major life transitions can lead to successful and satisfying outcomes, but they can also lead to failures and disappointments for young adults with a disability (Glidden & Jobe, 2007). Within these transitions, there are conflicts and dilemmas that everyone will face during their lifespan. However, educators, diverse families, and friends of the individual with a disability often wonder what quality of life the individual will experience. People involved in the individual's life want him or her to be set up for successful outcomes, but that person's quality of life is not always what we intended for it to be.

For many individuals with disabilities, quality of life can be hindered by caregivers or parents making decisions for them (Emerson et al., 1996). Often, individuals with disabilities possess a quality of life that they are pleased with, which is due to the meaningful supports in place (Del Bianco & Accorsi, 2019). Due to the COVID-19 Pandemic, one's overall quality of life has taken on a whole new meaning (TIME, 2020). Families are faced with unique challenges due to

the COVID-19 Pandemic when it comes daily routines, social supports, and overall support for their young adult with a disability (Redquest et al., 2020)

COVID-19 and Individuals with a Disability

COVID-19 can be spread human to human via droplets (i.e., spit, eyes, hands). People with disabilities are at a higher risk for contracting COVID-19 due to multiple factors (i.e., physical contact with caregivers, respiratory infections) (Trummers et al., 2020). Often individuals with disabilities are at an increased risk due to limited mobility (i.e., direct contact with service providers), preventative measures (i.e., social distancing, handwashing), and unable to communicate symptoms of the illness (Center for Disease Control, 2020). Additionally, individuals with intellectual or developmental disabilities are at a higher risk of mortality if they live in a group home and have a caregiver (Mozes, 2020). Individuals with disabilities often depend on caregivers and family members to care for them (NIH, 2020). No one would have imagined what one's quality of life would look like when the COVID-19 Pandemic wreaked havoc on the economy. The opportunity to work was no longer even an option for many with or without a disability.

Definition of Quality of Life

The World Health Organization (2020) defines "*Quality of Life*" as one's perception of his or her position in life. Quality of life relates to one's culture, values, goals, expectations, and standards. *Quality of life* is broad and associated with one's health, psychological well-being, belief system, social relationships, and how they relate to one's environment. Merriam Webster Dictionary (2020) defines 'quality' as a degree of an essential character, feature, role, rank, characteristic, accomplishment, and degree of excellence. 'Life' is defined as the period of birth to death, manner of one's living, one's being, and period of existence (World Health Organization, 2020). This manuscript will address the following: (a) defining one's of quality of life, (b) self-determination as a component of quality of life during the COVID-19 Pandemic, (d) personal and meaningful relationships during this challenging time, (e) choice as a necessary component of life, and (g) conclusions and implications.

Defining One's of Quality of Life

For some, quality of life may involve pursuing dreams, accomplishing goals, and living life to the fullest (The ARC, 2019). Other individuals may be content with where they are at in the present moment. When it comes to individuals with disabilities, we want to see our young adults live a life in which they may be able to experience independence, have a job where they receive a paycheck, and live a life where they can enhance their outcomes (Center for American Progress, 2019; Emerson et al., 1996). However, the term moves away from the traditional dictionary definitions and focuses on personal outcomes for the individual.

Emerson et al. (1996) expressed that quality of life is one in which one receive full supports in community life, and are supported in developing independence and skills. They are given choices to have control of their life, and are treated with high respect in an environment that is safe and secure for them. Additionally, the nature and quality of supports that one receives appear to play a vital role in determining one's quality of life (Beadle-Brown et al., 2016). When considering one's quality of life, caregivers of individuals with disabilities need to be aware of the individual with disabilities goals and aspirations for the future (Hensel et. al, 2002).

Self-Determination as a Component of Quality of Life

An important component to enhance the quality of life is improving the individual's life (Wehmeyer & Bolding, 2001). Self-determination has two significant meanings. Self-determination refers to one having control over his or her life and destiny. Wehmeyer and Bolding (2001) noted that individuals with disabilities need to be provided opportunities to be "*causal agents*" in their own lives by making decisions and choices without any external influences (Wehmeyer, 2014). Self-determination is defined as one who makes choices or decisions regarding his or her quality of life and who acts independently (Wehmeyer & Schalock, 2001). There are four characteristics to self-determination: (1) the individual with a disability acts autonomously, (2) behavior is self-regulated, (3) the individual with a disability is empowered to initiate and respond on their own and, (4) the individual with a disability acts in a self-realizing manner. Individuals with disabilities must act with these intentions that will help shape their future, tremendously improving their overall quality of life (Wehmeyer, 2014). Some individuals with disabilities possess the qualities of self-determination and self-advocacy, but experience loneliness when it comes to forming meaningful personal relationships with friends. During this time of social isolation, it is important for individuals with disabilities to be provided with opportunities to choose and select what they want to wear during the day, what they want to watch on television, and be purposeful and have an active role in the process. This will allow individuals with a disability to still advocate for themselves and allow for them to still practice self-advocacy during a crisis. Daily life during this COVID 19 Pandemic and staying at home does not mean individuals with disabilities do not have the right to be autonomous and remove one's right to display self-determination in everyday life (Wehmeyer, 2014).

Personal Relationships

Personal relationships are significant for individuals with disabilities, and they are a necessary component to improving their overall quality of life (Kim, 2019). McVilly et al. (2006) defined loneliness as an unpleasant feeling or emotion that may arise from decreased social interactions. Due to the COVID-19 Pandemic many individuals with disabilities are experiencing personal feelings of loneliness, feelings of inadequacy, and social isolation (McVilly et al., 2006). Many individuals expect to get some emotional component from friendships, but sometimes they do not get what they want or need in return. Often individuals with disabilities experience peer rejection, isolation which can impair one's overall quality of life. Additionally, this greatly affects one's overall quality of life as they transition into adulthood (Papoutsaki et al., 2013).

There are two distinct dimensions of loneliness. First, a social dimension where these interpersonal interactions result in a personal belonging within a social realm, however this is greatly limited due to the current pandemic (i.e., friends, social relationships) (Papoutsaki et al., 2013). Second, is the emotional dimension, where the individual finds that the relationship formed is meaningful and rewarding on a higher level of intimacy (i.e., feel supported, accepted, included) which can be quite difficult in determining during social isolation (McVilly et al., 2006).

Individuals with disabilities often face challenges when forming relationships. One of the most important factors is finding a stable and rewarding relationship (McVilly et al., 2006). Individuals with disabilities need opportunities to form social networks, emotional support, help with decision-making, and assistance in order to develop and sustain meaningful relationships.

Just because one is staying at home does not mean that there cannot be innovative ways to engage in meaningful relationships.

Individuals with an intellectual disability experience more loneliness than their typical peers without disabilities. Stancliffe et al. (2007) found that there is a greater risk of loneliness for adults with disabilities because they have fewer opportunities to engage in social interactions. It is important for individuals with disabilities to feel accepted within their neighborhood and community, but sadly they do not really feel a part of their communities (Stacliffe et al., 2007). The majority of individuals with disabilities experience fewer friends and greater social isolation due to their smaller social networks. Adults living with disabilities tend to be very lonely within their home setting, and are afraid to go outside or out of their comfort zone to form these meaningful relationships (i.e., friends) (Stacliffe et al., 2007).

Due to the COVID-19 Pandemic is important for young adults with disabilities to be provided with opportunities to engage with their friends in social activities rather it be through various social platforms such as ZOOM, Facetime, and Skype. Planning online game nights (i.e., bingo, trivia) allowing for minimal social interaction, but also adhering to the guidelines recommended by the Center for Disease Control and Prevention (CDC, 2020). Planning virtual online events allows individuals with disabilities to display self-advocacy. All humans thrive for interaction and this an essential component for individuals with disabilities during the COVID-19 Pandemic to have access to friends.

Choice as a Necessary Component of Quality of Life

Some scholars argue whether a choice is a necessary component of the quality of life. Neely-Barnes et al. (2008) researched choice and quality of life to see if choice affected larger residential settings, if the choice positively correlated with quality of life measures and if individuals with disabilities living in smaller settings experienced a better quality of life. The National Core Indicator (NCI) survey was used to assess the overall quality of life of participants in the study who were provided choices (Neely-Barnes et al. 2008). The NCI surveyed the individual with a disability, their family members, and service providers. The survey questions included: (a) demographics, (b) residence, (c) diagnosis, (d) health,(e) services,(f) self-determination, and (g) behavior supports.

It included questions about home and work setting activities, friends, rights, and family members (Neely-Barnes et al., 2008). A random sample was selected, and 224 respondents were chosen for the study. Choice-making opportunities were readily available in smaller living arrangements. Individuals who had other people represent them on the survey exhibited less influence over their choices. The level of disability was also affected by the choices of living arrangements. Individuals with disabilities who could answer for themselves experienced greater respect for rights and social inclusion. Individuals with disabilities who lived in smaller settings also received greater support from their families. Individuals with disabilities who lived within their community tended to make more choices, having an overall greater quality of life (Neely-Barnes et al., 2008). Their rights were acknowledged more frequently than those who could not answer for themselves.

Individuals with severe disabilities often live in larger settings where their quality of life was not experienced to the fullest (AAIDD, 2015). Their barriers included fewer choice-making opportunities and participation in activities. They often were unable to form significant relationships, and their choices were not respected (Neely-Barnes et al., 2008). Implications of this study raised questions as to whether if individuals with disabilities who are non-verbal have adequate opportunities to make choices in their daily lives.

Individuals with disabilities need to be provided with opportunities to be successful in everyday life (AAIDD, 2015; Neely-Barnes et al., 2008). However, quality of life is different for all individuals with disabilities. Choices are not always made independently by persons with disabilities. Choices are sometimes made for individuals with disabilities due to their degree of disability. It is vital during this COVID-19 Pandemic that individuals with disabilities are given the opportunity to make choices and self-advocate. Choices can include and not limited to the following: (1) what he/she wants to eat, (2) what he/she wants to watch on television, (3) who he/she wants to talk on the phone with, (3) what he/she chooses for exercise, and (4) when he/she wants to take a shower (AAIDD, 2015).

Conclusions and Implications

Throughout our lives, we make choices. These choices affect what we are going to wear, eat, shop, and affect our daily activities. However, some choices significantly impact our daily lives (i.e., employment, living arrangements, and medical decisions) (DeVito, 2016). Choice making is a core element of self-determination, and it is critical for all individuals with disabilities (Agran et al., 2010). Parents, guardians, and caregivers can provide informed choice-making opportunities. Making informed choices allows for the young adult with a disability to experience a degree of control in their lives. Making informed choices will enable individuals with a disability to make a choice but also be aware of the potential advantages and disadvantages of those choices (i.e., cause and effect) (Mitchell, 2015).

Families play a vital role in promoting self-determination in their young adult (Wehmeyer, 2014). Wehmeyer (2014) states that families have a hard time “letting go,” and it can be quite overwhelming (i.e., COVID-19 Pandemic), but families need to help their child at a young age to explore autonomy and allow their son or daughter to achieve unlimited possibilities. Thus, allowing all individuals with disabilities to be self-determined across their life span (i.e., implementing before middle and high school). It is important during these unique challenges that individuals with disabilities voices and perspectives are heard (John Hopkins University, 2020). Empowering parents to let their young adult make choices and decisions regarding their living arrangements, friends, and lifestyles will provide individuals with disabilities with unlimited options and success for their future.

Quality of life for individuals with disabilities varies with each individual and is different for each parent who has a child with a disability. Schalock et al. (2007) suggested that services, improvement strategies, and supports need to be put into place to enhance individuals with disabilities' personal outcomes. Due to COVID-19 restrictions varying from state to state, this may look different for each individual. However, it requires families, caregivers, and community members to think differently about how they can best serve individuals with disabilities.

Educators, family members, and caregivers must provide opportunities for self-determination, self-advocacy, role-playing, and turn-taking across settings (AAIDD, 2015).

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