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Choice Making and Individuals with Significant Disabilities

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Abstract

This literature review addresses issues and trends pertaining to choice making for individuals with significant disabilities. The benefits and development of choice making will be addressed, followed by a summary of several barriers to choice making. The review concludes with a synthesis of strategies and interventions for increasing effective choice-making opportunities, including choice-making formats, teaching choice making, and building choice making into daily contexts.

Self-Determination and Choice Making

Self-determination has been defined as, “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2006, p. 117). Although individuals with significant disabilities often require extensive supports to perform daily tasks and activities, this does not imply that they cannot become the causal agent in their life. Being a causal agent in one’s life infers that one has the ability to let others know when assistance is needed or when one wishes to not participate in a given activity (Wehmeyer & Field, 2007). Acting in a self-determined manner has never implied that a person must be fully independent in the daily functioning and not require assistance with daily tasks. Wehmeyer and Field (2007, p. 3) indicated that self-determination develops as people acquire four essential characteristics of self-determined behavior: 1) acting autonomously; 2) self-regulating behavior; 3) initiating and responding to events in a psychologically empowered manner; and 4) acting in a self-realizing manner. To act autonomously, a person must have an awareness of and ability to act upon his or her own preferences, interests, and abilities. Self-regulation infers that a person is able to examine his or her environment and act upon those observations to make choices that reflect his or her evaluation of potential actions. Being psychologically empowered consists of an individual developing personal self-efficacy toward the capacity to perform personally influential behaviors with the anticipation of expected outcomes. The final characteristic of self-realization involves the person gaining an awareness and knowledge of their strengths and limitations, and acting upon these strengths to better his or her situation.

One of the most basic building blocks leading to enhanced self-determination is the ability to make informed choices for opportunities within one’s daily life. Considering the skills

involved in becoming self-determined, choice making is one of the first and most basic skills to develop and build upon. Choice making has most commonly been referred to as the, “selection of an item or activity from an array of options at a particular moment in time” (Romaniuk & Miltenberger, 2001, p. 2). Although this definition has been simplified to the selection of an item or activity from available options, there are multiple steps that go into making choices.

The purpose of this review is to (a) explain the benefits of choice making; (b) summarize the development of choice making for individuals with significant disabilities; (c) detail several barriers to choice making for individuals with significant disabilities; and (d) provide strategies and interventions for increasing effective choice making opportunities.

Benefits of Choice Making

There are numerous studies identifying the benefits of choice making for individuals with significant disabilities. Increased choice making has been strongly correlated to higher quality of life outcomes (Willis, Grace, & Roy, 2008). It has also been shown that those individuals who live in the community and have more choices in daily living activities have higher scores on quality of life indicators (Neely-Barnes, Marcenko, & Weber, 2008). Adults with significant disabilities are often provided opportunities to live in the community with the choice of roommates. Individuals who are given the choice of who to live with are far more likely to have higher outcomes on quality of life indicators (Stancliffe et al., 2011).

Choice making has been used as a component in a variety of interventions, including increasing task engagement (Dunlap et al., 1994), increasing spontaneous speech production (Dyer, 1987), improving student performance on curricular materials and interventions (Cole & Levinson, 2002), improving general and specific behavioral concerns (Carr & Carlson, 1993; Dyer, Dunlap, & Winterling, 1990; Lindauer, Deleon, & Fisher 1999), developing early

communication skills (Stephenson & Linfoot, 1995), and increasing social interaction with general education peers (Kennedy & Haring, 1993).

Development of Choice Making

Although choice making is one of the most basic skills to develop, there are many individuals with significant disabilities who have not developed the ability to make informed choices, or often may even lack the opportunity to develop the ability (Bambara, 2004). Some practitioners and professionals in education and social services have expressed doubt that people with significant disabilities have the ability to make choices for themselves (Guess, Benson, & Siegel-Causey, 1985). Although professionals may not have confidence in the development of choice making in these individuals, research has shown that individuals with significant disabilities are capable of making choices regarding their daily living activities (Lancioni, O'Reilly, & Emerson, 1996). The development of choice making can be divided into four areas or skills: (a) freedom and opportunities for choice making; (b) familiarity with choice options/activities; (c) individual initiative to make choices; and (d) the development of skills and methods for making selection of choices (Brown & Brown, 2009).

Freedom and Opportunities for Choices

The first element of choice development is the individual's right or entitlement to making a choice. It is a philosophical belief that all people, including people with significant disabilities, have the right to make choices regarding aspects of their life (Brown & Brown, 2009). Despite the right and entitlement to choice making, individuals with significant disabilities have historically been limited in their opportunities to make choices (Cannella, O'Reilly, & Lancioni, 2005; Stancliffe & Abery, 1997). Kearney, Bergan, and McKnight (1998) conducted a study showing that individuals with significant disabilities who lived in more restrictive living

situations (i.e., large group home settings) had far fewer choice making opportunities when compared with people in less restrictive settings (i.e., single or double occupant apartments, smaller group homes). Rarely are personal preference and choice involved in the vocational placement of individuals with significant disabilities (Martin, Woods, Sylvester, & Gardner, 2005). The lack of opportunities creates a barrier for the overall development of choice-making skills and, presumably, self-determination.

An increase in opportunities to make choices has been shown to increase independence and improve quality of life outcomes for individuals with disabilities. Browder, Cooper, and Lim (1998) conducted research on the outcomes of direct care staff providing choices within daily living contexts. In this study, individuals with disabilities were provided with opportunities to choose locations in which they would participate in leisure activities. As a result of the opportunity to choose the setting of activities, participants increased their ability to effectively communicate their desires. Research has also shown that offering choices to children with significant disabilities can result in positive behavior outcomes. Lohrmann-O'Rourke and Yurman (2001) used increased choice making opportunities for preferred play items during problem activities to reduce challenging behaviors. Often, support providers or practitioners use directives rather than allowing choices when working with individuals with significant disabilities (Moes, 1999). Cole and Levinson (2002) conducted a study comparing the effects of student responses to verbal directives or in response to choice questions within instructional routines for students with developmental disabilities. The two conditions were observed and results indicated far fewer challenging behaviors in the choice questions condition. An additional result was when provided choice opportunities there was an increase for each student in completion of more complex steps prior to challenging behaviors. The research results of

these studies (Browder, Cooper, & Lim, 1998; Cole and Levinson, 2002; Lohrmann-O'Rourke & Yurman, 2001; Moes, 1999) have shown that when individuals with significant disabilities are provided choices they have greater independent living outcomes and increased quality of life outcomes.

Familiarity with Choice Options

For people with significant disabilities to make choices effectively and as independently as possible, they must be familiar with the choice options available, but having experiences with the options and realizing the consequences of the possible choices (Wehmeyer, 2007). As noted previously, many individuals with significant disabilities have limited opportunities and therefore must be exposed to new choice options. It is the responsibility of the teacher, support staff, family members, and others working with the person to ensure that he or she gains experiences and familiarity with possible choice options within and across various settings (Brown & Brown, 2009). Shevin and Klein (1984) defined choice as, "the act of an individual's selection of preferred alternatives from among several familiar options" (p. 160). This definition of choice implies that the individual is familiar with the options available and must have regular, consistent choice making opportunities throughout his or her daily living experiences. Cannella, O'Reilly, and Lancioni (2005) further emphasized that individuals with significant disabilities must not only be familiar with their choices, but must be able to identify their preferences within the choice options. It is when a person makes choices based off their preferences that they are acting in a self-determined manner (Deci & Ryan, 1985).

Individual Initiative

Even when there is the presence of multiple opportunities in an environment that promotes opportunities to choose, the person must initiate choice-making actions. Hickson and

Khemka (2001) reported that research has shown that cognitive, motivational, and emotional factors interplay in the choice making process. These researchers also reported that self-awareness of personal capabilities and confidence are key elements of building personal initiative. According to Hickson and Khemka (2001), the development of intrinsic motivation is key to demonstrating initiative, and intrinsic motivation occurs from “maintaining an individual’s sense of choice over what happens and the ability to act on and adapt to environmental surroundings more competently” (p. 199). Support and encouragement have also been identified as key elements to developing and promoting initiative and self-evaluation for individuals with significant disabilities (Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009).

Methods and Skills in Choice Making

Many individuals with significant disabilities have challenges with expressing their needs and desires when making choices (Lancioni, O’Reilly, & Emerson, 1996). Antaki, Finlay, Sheridan, Jingree, and Walton (2006) reported that even when individuals with significant disabilities are attempting to make a choice, they often lack the expressive communication skills needed to independently make the choice and therefore require extensive support from others to facilitate the expressive communication.

Due to this complexity of intellectual disability, Brown and Brown (2009) recommend that an individual’s skills be assessed across all possible life areas. This requires support teams to work collaboratively with families to determine the skills and needs for each person. To fully support a person with significant disabilities, the support team must be aware of the communicative methods and needs that the person has within various settings. Browder, Cooper, and Lim (1998) emphasized the importance of support teams working to enhance the communication skills of people with significant disabilities to enable them to be more

independent in choice making. All people with significant disabilities can learn to communicate more effectively, yet it is through individualized support that a person develops the ability to express his or her wants and needs. Herr and O'Sullivan (1999) reported that support staff members have the professional obligation to learn how to understand the person with significant disabilities, and then to respect and follow the choices that are expressed by a person with a disability. It is further the support staff's responsibility to teach a person with a significant disability how to evaluate effective choices in his or her life.

Barriers to Choice Making

There can be many barriers to choice making for individuals with significant disabilities. The barrier of having fewer choice-making opportunities was addressed previously, but there are other barriers to choice making beyond having fewer opportunities, including: (a) the urgency that some decisions require; (b) adherence to common rules and procedures; and (c) lack of proper training in enhancing choice making.

Individuals with significant disabilities often take longer to process information and may take longer to make choices. Bratkovic, Bilic, and Nikolic (2003) noted that individuals with significant disabilities often lack the skills necessary to process information quickly enough for choices and decisions that must be made immediately. This can create a barrier if a choice needs to be made quickly without time to process. These types of situations might include safety related issues (e.g., injuries, fire, street safety), unchangeable times/periods (e.g., cooking times, doctor appointments), and transition times (e.g., getting on a bus/train, getting to work).

Cameron and Murphy (2002) reported that there are many times during transitions to activities where choice opportunities are limited.

In life there are common rules and procedures that must be followed to maintain safety. People driving cars must adhere to driving regulations or they will lose their driving privileges or will be required to pay fines. A home owner must pay his or her mortgage and renters must pay their monthly rent. Although these technically could be considered choices of whether to adhere to the rules or expectations, there can be severe consequences for not adhering. Robertson et al. (2001) emphasized how these rules essentially take away our individual freedom of choice for the overall welfare of society. Within the realm of common rules and procedures, there is also the barrier of common procedures used within adult disability services. Many individuals with significant disabilities live in congregate settings where many choice making opportunities are not available due to staffing concerns, common home rules, or lack of independence within the setting (Robertson et al., 2001).

Another common barrier is the lack of training that many care providers, school staff, and family members have regarding methods of enhancing choice making opportunities. These people often have little training or background in the development and enhancement of choice making, and therefore inhibit individuals with significant disabilities from maintaining their freedom of personal choice on daily activities (Martin, Woods, Sylvester, & Gardner, 2005). Ruef and Turnbull (2002) identified the need for support providers to develop skills in listening and responding positively to choices made by individuals with significant disabilities they support. Without direct training these support providers could become a barrier to choice making opportunities.

Strategies for Increasing Choice Making Opportunities

Increasing choice making opportunities for individuals with significant disabilities takes a lot of support from educators and support providers. Research shows that it is possible to train

people who work closely with individuals with significant disabilities to increase choice-making opportunities (Cannella, O'Reilly & Lancioni, 2005). There are several themes that emerge in the literature as strategies educators and support providers should consider for increasing choice-making opportunities of individuals with significant disabilities. These themes are choice-making formats, teaching choice-making skills, and building choice-making opportunities into daily contexts.

Choice-Making Formats

Kearney and McKnight (1997) discussed common procedures for assessing preference in individuals with disabilities (though not specifically significant disabilities), including interviews and questionnaires, pictorial representations, technology and direct observation. Interviews and questionnaires can be given directly to the individual with a disability or to a parent, teacher or caregiver. Interviews and questionnaires given to someone other than the individual should, however, be used cautiously. Parsons and Reid (1990) studied nineteen individuals with significant disabilities who did not speak and showed that support provider opinions on the participants' preferences did not always reflect what that individual actually chose. Proxy opinions are not always indicative of true preference (Parsons & Reid, 1990).

Pictorial choice making involves using pictures of objects, instead of the actual objects. This increases choice-making opportunities because people with significant disabilities can select from objects that are not in the immediate environment (Parsons, Harper, Jensen & Reid, 1997). Not all people with significant disabilities can effectively make choices through pictures. Parsons, Harper, Jensen & Reid (1997) studied the choices of seven adults with severe disabilities, five of whom could make effective choices about leisure activities only with objects and two of whom could make choices with objects and pictures.

Technology, as a choice-making format, involves the use of a microswitch or a computer or some other form of technology to make a choice. The rapid development of technology to facilitate the communication of preferences has expanded the choice-making opportunities of individuals with significant disabilities. There is a body of literature on the use of microswitches to enhance choice-making opportunities for individuals with significant disabilities. “A growing body of research is showing that the availability of assistive aids, such as microswitches, may enable individuals with profound multiple disabilities to participate more constructively in activities and attain control over specific aspects of their environments” (Tam, Phillips & Mudford, 2011). One microswitch can be used to activate a known preferred stimuli or more than one microswitch can be use to make a choice between multiple options. Research has shown that microswitches can effectively be integrated in choice making opportunities for individuals with significant disabilities (Kennedy & Haring, 1993; Tam, Phillips & Mudford, 2011).

Direct observation has been the primary method of assessing preference of individuals with disabilities (Kearney & McKnight, 1997). Direct observation involves observing what choice a person makes when provided with a choice-making opportunity. Key areas to consider when discussing choice-making formats include how the choice options are presented and how choices are made. Choice options can be presented in a single stimulus format, paired stimulus format, multiple stimuli with replacement format, multiple stimuli without replacement format, and free operant assessment format (Cannella, O’Reilly & Lancioni, 2005). A single stimulus format is when one object is presented and the person chooses whether or not to engage with that object. A paired stimulus format is when a person makes a choice between two objects. In a multiple stimuli with replacement format there are three or more objects from which to choose and when

that object is selected, it is replaced with a new object. If the chosen object is not replaced, that is multiple stimuli without replacement format. Free operant assessment formats have multiple objects and the person is free to engage or not with any of the objects. Individuals with significant disabilities may be capable of making choices from any of these formats and it is important that the choice-making format matches the person's present skills (Parsons, Harper, Jensen & Reid, 1997). To determine what format is appropriate for a person, Parsons, Harper, Jensen and Reid (1997) recommended presenting options along the continuum of the formats and evaluating in which formats the individual can successfully make choices.

Not only can choices be presented in multiple formats, but also a person can make a choice in multiple ways. Engaging in choice making by individuals with significant disabilities can involve many challenges due limited communication skills and limited mobility. Individuals with significant disabilities often lack skills or knowledge to communicate preference because of limitations in the ability to communicate preferences with verbal skills, facial expressions, avoidance behaviors and motor skills (Shevin & Klein, 1984). For example, a person can make a choice of a snack by saying what she wants, smiling when the snack she wants is presented, refusing to eat a snack she does not want or by reaching for the snack she wants. A person with a significant disability may have problems in one or more of these behaviors used to express choice. As such, individuals with significant disabilities often rely on highly individualized behaviors to express preferences and make choices, such as looking at an object, movement, vocalization and facial expressions (Sigafoos & Dempsey, 1992). Highly personal behaviors can be an effective method of choice making. An example of using a personalized movement to make a choice is a person who turns her head to the choice she wants. Personalized vocalizations and expressions can be used in a similar manner to make a choice. A study

involving three children with severe disabilities (Sigafoos & Dempsey, 1992) showed the participants successfully making choices, including refusals, with highly personal actions. Choices were made by looking at an object, looking at an object and then smiling, or looking at an object and vocalizing and reaching for the object. Parents and educators can use a similar design to determine what highly individualized actions the person uses for choice making (Sigafoos & Dempsey, 1992).

Teaching Choice-Making Skills

Often, choice making is thought of as just an opportunity that needs to be enhanced. For example, the belief is often that we need to provide individuals with significant disabilities more opportunities to make choices. While this is true, it misses a critical step: students with significant disabilities need to be taught choice-making skills. Increasing choice-making opportunities has limited utility if people with significant disabilities are not taught how to make choices. “Choice making is a viable teaching target, to be subjected to task analysis, planning, implementation and evaluation similar to those which are characteristic of more traditional content areas” (Shevin & Klein, 1984, p.162). Most people learn to make choices informally by following the example of others as a young child. This is often not the cause for individuals with significant disabilities, who often require a lot of support and targeted intervention to learn how to make choices (Shevin & Klein, 1984). Because people with significant disabilities too often have had limited experience making choices, these interventions can be time consuming (Lancioni, O’Reilly & Emerson, 1996).

There are three components of choice-making skills: cognitive/ discrimination, affective, and generalization skills (Shevin & Klein, 1984). Cognitive/ discrimination skills are those that enable a person to discriminate between choice options. Affective skills are the skills needed to

recognize preferences. Generalization skills are those that enable a person to engage in choice making in real life contexts. For example, a person needs to be able to discriminate between two beverages, know that she likes milk and does not like tea, and then be able to express preference between the two in a variety of settings such as at restaurant, school and home.

In deciding upon choice-making goals, a good place to start is to look at how people in general make choices and how a person with a significant disability is currently making choices (Shevin & Klein, 1984). The person with the disability may be making choices, but perhaps in a manner that is ineffective and/or unacceptable, such as screaming, crying, throwing, and so forth. Some strategies that have been effective in teaching choice-making skills are errorless teaching with time delay, response prompting, response fading, and measures against positional responding (always choosing the object that is in a certain position such as on the left).

Building Choice-Making Opportunities into Daily Contexts

Choice-making opportunities must be integrated into daily contexts. Some contexts that are commonly used for choice-making interventions in the research are meal and snack times, leisure situations, and occupational settings (Lancioni, O'Reilly & Emerson, 1996). Shevin & Klein (1984) discussed five choice opportunities: choosing among activities, choosing whether or not to engage in an activity, choosing when to terminate an activity, choosing alternative means of accomplishing an objective, and choosing a partner. A good daily context to illustrate these five opportunities is leisure time. A person with significant disabilities can choose whether to listen to music or to watch television. Or that same person can choose whether or not to join others in a card game. If the person chooses to watch television, then he or she can also choose when to stop watching television. Additionally a person could be painting during leisure time and when someone shows one type of paint, such as watercolor paints, he could choose another

type of paint, such as oil paints. If he is playing a game during leisure time he can choose who he wants to play that game with. These are all examples of a variety of choice-making opportunities integrated into a daily context.

Lancioni, O'Reilly and Emerson (1996) further distinguished choice-making opportunities as non-controversial (to be encouraged) and controversial (to be avoided). The examples of non-controversial choice-making opportunities include activity conditions, clothing arrangements, personal grooming, and leisure opportunities. Getting ready in the morning is a daily context that can illustrate these choice opportunities. An activity condition that a person can choose between is in what order he wants to get ready; for example does he want to brush his teeth first or wash his hair. When he gets dressed, he can choose what he wants to wear and then choose what cologne he wants to wear. Finally, when he is finished he can choose what he wants to do for a break; for example, sit outside or relax in his room. Some controversial choice-making opportunities are those that result in remaining excessively passive, avoidance of self-help skills, staying in bed, and rejecting health care procedures. Referring back to the morning routine example, it would be inappropriate most of the time to provide the following choice options: choosing just to sit and not get ready, choosing to let someone else brush his teeth when he can do it himself, choosing to stay in bed all day, and choosing not to have suctioning when needed. There are sometimes exceptions, such as it appropriate to choose to stay in bed all day when you are sick.

Conclusions

It is a human right to make choices regarding aspects of one's life, yet it has been documented that this right is often compromised for individuals with significant disabilities (Stephenson & Linfoot, 1995). The overall purpose of teaching and providing choice-making

opportunities to these individuals is to assist in the achievement of higher quality of life outcomes. One misconception regarding choice making and individuals with significant disabilities is that they are unable to make choices that result in the best personal outcomes (Bannerman, Sheldon, Sherman, & Harchik, 1990). As suggested by this review of the research, individuals with significant disabilities are able to develop the ability make choices regarding daily routines and activities, but often require more extensive and direct instruction. To make such choices, individuals must have the opportunity to develop personal interests in activities or items being offered in the choice making contingency. Far too often individuals with significant disabilities are not provided opportunities to determine personal preferences, which further limit their ability to successfully make choices (Lancioni, O'Reilly & Emerson, 1996). Other possible reasons for limiting the opportunities for choice making have included a lack of awareness on the part of support providers on how people with significant disabilities could make choices, or others setting short- or long-term goals for the person with the disability that result in more limitations to personal choice (Dattilo & Mirenda, 1987).

Another misconception regarding choice making and individuals with significant disabilities is that they are unable to consistently be purposeful in choice making. Purposefulness refers to the intentionality of the selection that is made in a choice opportunity (Lancioni, O'Reilly & Emerson, 1996). When initial making selections in the choice-making format, individuals may select a choice that was not what they intend or realize, but research has shown that people with significant disabilities are able to develop the ability to consistently be purposeful in choice making (Derby et al., 1995; Fisher et al., 1992; Houlihan et al., 1992; Paclawskyj & Vollmer, 1995).

As research has shown, providing the opportunity for individuals with significant disabilities to make choices has positive outcomes. Choice making has been used for increasing the frequency of appropriate food and drink requests (Fisher et al, 1992), increasing engagement in sensory stimulation activities (Buyer, Berkson, Winnega, & Morton, 1987), increasing vocational placement options (Martin, Woods, Sylvester, & Gardner, 2005), reduction of problem behaviors (Cannella, O'Reilly & Lancioni, 2005), increasing task engagement (Lancioni, O'Reilly & Emerson, 1996), and other activities and skills.

There are several overall benefits to teaching choice making to individuals with significant disabilities. Choice making promotes the enhanced personal autonomy of individuals with significant disabilities. Because individuals with significant disabilities often require supports to perform daily living tasks and activities, that does not mean they cannot become a causal agent in their life (Wehmeyer & Field, 2007). They have the capacity to learn how to let others know when they need assistance or when they wish to not participate in a given activity. Acting in a self-determined way has never implied that a person with significant disabilities must be fully independent in daily functioning and not require assistance with daily tasks. The field of special education and rehabilitation services has continually sought to improve quality of life outcomes for people with significant disabilities, and teaching choice making is one way to promote higher quality of life. Individuals with significant disabilities can live fulfilling lives and feel autonomous in their life by making choices during daily living activities. Research has shown that people with significant disabilities can make choices, but in many cases need to be taught the choice-making process (Bambara, 2004; Lancioni, O'Reilly & Emerson, 1996).

This review suggests that there are several areas of research that require further investigation. With the requirement in special education on the individualized educational

program (IEP), there should be further research conducted on the level of opportunities involving choice making that is incorporated into the IEP. From the research that has been conducted in the past, it would be hypothesized that there are limited choice opportunities available in the IEP process and the development of annual goals and transition planning. Individuals with significant disabilities should have the opportunity to become self-advocates and make choices regarding their IEP goals and future planning. Related to the IEP process, research should be conducted on the use of person-centered planning and the inclusion of personal choice-making opportunities throughout the lifespan.

Limited research has been conducted comparing the effectiveness of different choice-making interventions and strategies. Choice-making research has focused primarily on measuring the effectiveness of one specific intervention or strategy, but has not evaluated interventions or strategies compared to one another to determine which are more effective than others. It would be additionally beneficial for interventions and strategies to be evaluated with a variety of different participant groups (e.g., verbal v. non-verbal communication, mild v. severe disabilities, school-based v. community-based v. home-based). Kearney and McKight (1997) and Bambara (2004) suggested that research on choice making needed to focus on longitudinal experiences and conducted in a variety of settings and activities. There are currently no longitudinal studies on the long-term effects of choice making interventions and strategies. Other possible research areas of focus might include the incorporation of preference assessments into daily living activities and life choices, and how to overcome the barriers to training care providers to create more opportunities for choice making. Overall, the theme of choice-making research appears to be, “We’ve made a lot of progress but still have a long way to go” (Bambara, 2004).

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