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What Should Service Providers Know When Measuring How They Impact Consumers' Freedom to Make Choices?

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Abstract

Choice is now recognized as a fundamental right of persons with intellectual and developmental disabilities (IDD) in the United Nations Convention on the Rights of Persons with Disabilities. In Ontario, the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act *requires providers of services for adults with IDD to support them in making choices. However, efforts to implement services that promote choice have been limited by the lack of a practical understanding of choice. In this scoping review, the scientific literature on choice is contrasted to the lived experience of persons with IDD to both clarify the meaning of choice and identify what components of choice should be measured when evaluating IDD services. Through a review of the English-language literature published between January 1, 1991 and December 31, 2011, four components were identified as necessary for choice to occur: the availability of choice opportunities, the provision of choice options, an informed cognitive process and act of choosing, and a supportive environment. Feedback on these findings was sought from a range of stakeholders, including persons with IDD, family members, and representatives from service agencies that support persons with IDD. The results of these consultations are presented. Challenges with implementing the concept of choice at the service level is discussed.*

Experiencing choice contributes to individuals' quality of life, self-image, and self-expression by allowing them to engage in valued and meaningful tasks (Brown & Brown, 2009; Brown, 1992; Guess, Benson, & Siegel-Causey, 2008; Kearney & McKnight, 1997; Schalock et al., 2002). However, persons with intellectual and developmental disabilities (IDD) often face challenges in making choices. Prior inexperience with choice may limit their knowledge or motivation to act on their choices (Agran, Storey, & Krupp, 2010; Brown, 2003). They may have difficulty expressing their choices or limited capacity for the cognitive processes sometimes required in more complex choices (Carlson & Wilson, 1993; Jenkinson, 1993; Lancioni, O'Rielly, & Emerson, 1996). Furthermore, choice may be intentionally limited by family or support staff out of fear of the potentially negative consequences of choices (Brown, 2003; Finlay, Walton, & Antaki, 2008). Supporting persons with IDD in making choices is therefore crucial. Policies and services for persons with IDD can play a significant role in promoting choice-making and increasing choice options and opportunities in the lives of persons with IDD.

The freedom to make choices is a fundamental right of all individuals, and has been reinforced in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006). Signatories must recognize the importance for persons with disabilities to have the "freedom to make their own choices." Reaffirming this right is particularly important for persons with IDD who, historically, have had limited choice due to practices of institutionalization and misguided beliefs that persons with IDD were not able to make choices (Agran et al., 2010). Persons with disabilities must also have their own choices recognized as equal to others in the community where they live (article 19; United Nations, 2006). The Convention demands that the freedom to make one's own choices be respected for all individuals with disabilities, as this is fundamental to one's dignity (article 3; United Nations, 2006). It therefore must be an important outcome of IDD policies and services aiming to improve the social inclusion and quality of life of citizens with IDD.

Supporting persons with IDD in making choices, and providing them with greater choice opportunities and options are increasingly recognized as a crucial process in providing high quality services. Currently, policies and services supporting persons with IDD in many countries aim to improve consumers' opportunities to actively engage in decisions related to the services they request and receive.

In Ontario, the Ministry of Community and Social Services introduced the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2008), which aims to improve the services and supports available to adults with IDD. The promotion of individual choices is central to the targeted service improvements. The identification of choice as a required service outcome is a welcome shift in policy.

When monitoring the quality and performance of IDD services and policies, attention should be given to the experience of choice among service consumers with IDD. This paper aims to inform quality improvement monitoring in services and policies for persons with IDD, and especially in their efforts to improve the experience of choice among the persons they support. The paper reviews the scientific literature on choice and contrasts it to the lived experience of persons with IDD. It clarifies what choice means in the lives of persons with IDD, and what components of this experience should be monitored to inform quality improvement in IDD services and policies. Its contribution is a proposed framework clarifying the components of choice that should be monitored to inform quality improvement in IDD services and policies. Such a framework is recognized as an important step in developing monitoring activities that will lead to useful and relevant knowledge (Buntinx & Schalock, 2010; Schalock & Verdugo, 2012; van Loon et al., 2013).

Methods

We performed a scoping review of the English-language literature from January 1, 1991 through December 31, 2011. Scoping reviews are "an approach through which an overview and critical analysis of existing evidence clarifies, defines, and develops conceptual boundaries within a topic or across a field of evidence" (Arksey & O'Malley, 2005; Davis, Drey, & Gould, 2009). They involve data collection and synthesis of existing research, although unlike systematic reviews, they do not intend to compare all published papers on the topic, nor do they assess the quality of the literature. Given the heterogeneity of the choice literature in its focus, as well as the large number of studies published about choice, a scoping review was considered to be the best approach.

Overview of Existing Evidence

The search strategy included: (a) a search of databases, including PsycInfo, Medline, Web of Science, Proquest, and ERIC using combinations of the following search terms: choice behaviour, decision making, self-determination, empowerment, personal control, participation, social inclusion, independence, autonomy, volition, and preference; and (b) a review of secondary references (cited in primary articles). Papers were selected if they met the following inclusion criteria: provided a definition of choice, identified factors that can promote or prevent choice, identified a method or tool to measure choice, or identified characteristics that should be included in a measure of choice. The review was not specific to the experience of choice of persons with IDD.

The first author conducted the literature search and reviewed articles using a data extraction form developed for this review. Descriptive characteristics were extracted from the articles, including definition(s) of choice, factors that were reported to promote or prevent choice, and methodological issues regarding the measurement of choice. Both authors met periodically to review the extracted information. The search was continued until saturation was reached and articles were not providing new information. The authors worked collaboratively to summarize and categorize components of the reviewed definitions into meaningful and coherent statements from which the core components of choice were identified. The findings of the scoping review were presented to a multidisciplinary research team for feedback and guidance in the preparation of this paper.

Critical Analysis of Existing Evidence

The MAPS research program had an advisory structure to inform the research team on the relevance and meaning of the study results in their contexts (Martin & Ouellette-Kuntz, 2014). The advisory structure included: (1) three Local Advisory Committees (LAC) composed of representatives of IDD service agencies, representatives of the ministry responsible for funding services for adults with IDD, and members of families of adults with IDD; (2) as well as three Consumer Consultation groups (CC) composed of six to eight adults with IDD. We presented the results of this review to our LACs, and the meeting facilitators prompted discussion with the following questions: How can the staff support consumers in making choices? How can we measure success in promoting choices? We presented the simplified findings from the scoping review to the Consumer Consultation groups and asked them to discuss the following questions: How can people and staff help you make choices? How can we know you have choices? What should we look at?

Results

Forty-four articles retrieved through the database and secondary reference searches met the inclusion criteria (until saturation was reached). The articles came from journals covering a range of disciplines, including disability studies, health care and medicine, psychology, rehabilitation, ethics, and social policy. Through our review, we identified four components of choice that are necessary for choice to occur. Each component is presented and discussed below, along with quotes from our advisory and consumer committees that reinforce definitions or identify potential issues in their implementation in practice. See Table 1 for a summary of what component(s) of choice were represented in each of the articles.

Component 1: The Importance of Choice-Making Opportunities

Opportunities need to be available in a range of situations for choice-making to occur (Agran et al., 2010; Brown & Brown, 2009; Cannella, O'Reilly, & Lancioni, 2005; Finlay et al., 2008; Hatton et al., 2004; Jenkinson, Copeland, Drivas, Scoon, & Yap, 1992; Jenkinson, 1993; Lancioni et al., 1996; Neely-Barnes, Marcenko, & Weber, 2008; Stalker & Harris, 1998; Stancliffe & Parmenter, 1999; Wehmeyer & Bolding, 2001). For most individuals, choice opportunities arise naturally through daily living, from deciding what to wear to vocational choices. However, for persons with IDD, these opportunities may be limited, with choices made by others around them (Agran et al., 2010; Mithaug, 2005; Robertson et al., 2001; Stancliffe, 2001). While support staff work on offering choice in a range of life situations, there are practical limitations on choice opportunities, such as living arrangement or finances. Committee members recognized that despite best efforts, individuals may still face restricted choice opportunities due to external circumstances: "we must consider geography when considering choice… such things as transportation can limit choice (LAC member, Kingston);" "ODSP [Ontario Disability Support Program; a government social assistant program that provides financial and employment supports to individuals with disabilities] doesn't give us a lot of choices, the way the rules are for work, it can get in the way (CC, Toronto);" and "some people, such as those who live in group homes, might have fewer choices because they have to abide by government rules (CC, Kingston)." Consumers frequently reported a desire to have more choice in where they live. However, there are many external factors that can determine place of residence that are outside the control of the person with IDD, such as their support needs and the availability of accommodation.

Table 1. Summary of the Component(s) of Choice Represented in Each Article

Author (Year)	*Choice-Making Opportunities*	*Choice Options*	*Cognitive Process and Performative Act*	*Supportive Environment*
Agran, Storey, & Krupp (2010)	Yes	Yes		
Algozzine, Browder, Karvonen, Test, & Wood (2001)				Yes
Bambara (2004)			Yes	Yes
Barron (2001)			Yes	Yes
Broadstock & Michi (2000)			Yes	
Brown (2003).	Yes		Yes	
Brown & Brown (2009)	Yes		Yes	Yes
Cannella., O'Reilly, & Lancioni (2005)	Yes	Yes		
Cobigo, Lachapelle, & Morin (2010)		Yes		
Cobigo, Morin, & Lachapelle (2009)		Yes		
Cobigo, Morin, & Lachapelle (2007)		Yes		
Dunlap, DePerczel, Clarke, Wilson, Wright, White, & Gomez (1994)		Yes		
Ekdahl, Andersson, & Friedrichsen (2010)			Yes	
Finlay, Walton, & Antaki (2010)	Yes		Yes	Yes
Fisher, Cea, Davidson, & Fried (2006)			Yes	
Fraenkel & McGraw (2007)			Yes	Yes
Fyson & Kitson (2007)			Yes	
Guess, Benson, & Siegel-Causey (2008)		Yes	Yes	Yes
Harris (2003)		Yes	Yes	Yes
Hatton, Emerson, Robertson, Gregory, Kessissoglou, & Walsh (2004)	Yes			
Ho (2008)			Yes	
Jenkinson (1993)	Yes			
Jenkinson, Copeland, Drivas, Scoon, & Yap (1992)	Yes			
Katz & Assor (2007)			Yes	
Kearney & McKnight (1997)			Yes	
Lancioni, O'Reilly, & Emerson (1996)	Yes			Yes
Mithaug (2005)	Yes	Yes		
Neely-Barnes, Marcenko, & Weber (2008)	Yes			Yes
Nota, Ferrari, Soresi, & Wehmeyer (2007)	Yes			
Ogden, Daniells, & Barnett (2009)		Yes		Yes
Robertson, Emerson, Hatton, Gregory, Kessissoglou, Hallam, & Walsh (2001)	Yes			

Table 1. Summary of the Component(s) of Choice Represented in Each Article (continued)

Author (Year)	*Choice-Making Opportunities*	*Choice Options*	*Cognitive Process and Performative Act*	*Supportive Environment*
Schloss, Alper, & Jayne (1993)			Yes	Yes
Sharot, Velasquez, & Dolan (2010)		Yes		
Sinding & Wiernikowski (2009)			Yes	
Smith, Morgan, & Davidson (2005)	Yes			
Smyth (2006)	Yes		Yes	
Stalker & Harris (1998)	Yes	Yes	Yes	Yes
Stancliffe (2001)	Yes	Yes	Yes	
Stancliffe & Abery (1997)		Yes	Yes	
Stancliffe & Parmenter (1999)	Yes			
Storey (2005)		Yes	Yes	
Wehmeyer & Bolding (2001)	Yes			
Williams (1998)		Yes		
Wiltz (2007)			Yes	
Total number (%)	19 (43%)	16 (36%)	23 (52%)	13 (29%)

When considering choice for persons with IDD, larger life choices such as living arrangements are sometimes viewed as more meaningful than day-to-day choices, such as what time to go to bed (Brown, 2003). However, feedback from our consumer consultations reinforced the importance of having choice in both day-to-day activities, as well as larger decisions. Persons with IDD want opportunities to make both small and large choices: “All choices are important. From what to eat to big medical decisions (CC, Thunder Bay).”

Choice opportunities must be appropriate for the person to whom they are offered. Offering age-appropriate opportunities fails to recognize that persons with IDD may have cognitive or communication limitations that may affect their choice making skills, and therefore may not be able to make the same types of choices as their same-aged peers. Opportunities that are based on individuals’ development, strengths and abilities are more understandable and feasible for the individual to whom they are provided (Mithaug, 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Robertson et al., 2001; Smith, Morgan, & Davidson, 2005; Smyth, 2006; Wehmeyer & Bolding, 2001). A committee member echoed this view that choice opportunities should match the individuals’ strengths and limitations: “Can they be successful at it? Can they actually do it? The [choices] have to match the individual’s abilities and needs (LAC, Toronto).”

Component 2: The Importance of Choice Options

Choice has been defined as the selection of one option over another, suggesting that two options may be sufficient. However, this does not reflect the choice experienced by persons without disabilities who typically have a range of options to select from (Agran et al., 2010; Guess et al., 2008; Stancliffe, 2001), including the possibility to reject all options and seek out other alternatives. In practice, limiting choice to two options likely means that other individuals are excluding potential options. For choice to occur, individuals should be provided with a range of choice options across all opportunities, with new options offered whenever available.

Making a choice between preferred options has been identified as a critical determinant of whether choice is experienced (Cannella et al., 2005; Cobigo, Morin, & Lachapelle, 2007; Cobigo, Morin, & Lachapelle, 2009; Cobigo, Lachapelle, & Morin, 2010; Dunlap et al., 1994; Harris, 2003; Kearney & McKnight, 1997; Mithaug, 2005; Williams, 1998). However, this does not reflect the reality of choice (Cannella et al., 2005; Sharot, Velasquez, & Dolan, 2010). Individuals often have to choose from undesirable options, and while the options may not be preferred or enjoyable, choice nevertheless occurs. The benefits of choice come from being offered and choosing from a range of options, not only those options that are preferred. The consumer committees highlighted the need to provide a range of choice options: "People can help us by giving us all the different choices (CC, Toronto)," and "It is nice to have new options…it is important to try new things (CC, Thunder Bay)."

Component 3: Choice is a Process and an Act

Choice involves two steps: a cognitive process and a performative act; both are required for choice to occur. The cognitive process is largely unobservable, involving the evaluation of the available options and identification of the option that best meets one's goals (Brown, 2003; Guess et al., 2008; Harris, 2003). The performative act of choosing is the individuals' expression of their choice through the physical act of selecting an option or communicating their selection to others (Cannella et al., 2005; Guess et al., 2008; Harris, 2003; Kearney & McKnight, 1997; Smyth, 2006; Stalker & Harris, 1998; Storey, 2005).

The process of choosing needs to be informed by an understanding of the available options (Stalker & Harris, 1998; Storey, 2005). For persons with IDD, lack of experience may contribute to a limited understanding of the available options. While offering options that are familiar to the person choosing may promote informed choice making in persons with IDD, over time, offering only familiar options may limit choice by preventing individuals from being exposed to novel options (Bambara, 2004; Kearney & McKnight, 1997; Stalker & Harris, 1998). Furthermore, this is not consistent with the reality of choice for persons without disabilities who are frequently required to select from options that they have no prior experience with (Smyth, 2006). What is essential for informed choice is not familiarity with the options, but rather the provision of appropriate information regarding the choice options and time to evaluate the options (Broadstock & Michie, 2000; Ekdahl, Andersson, & Friedrichsen, 2010; Fisher, Cea, Davidson, & Fried, 2006; Fraenkel & McGraw, 2007; Harris, 2003; Storey, 2005). When there are many potential options to choose from, persons with IDD may also benefit from having options presented in pairs or smaller groups to make the process of choosing easier. These ideas were echoed by our committee members: "For any choice, you need details on the options and to understand what they mean and what will happen if you choose that option (CC, Thunder Bay)," and "we need enough time to think in order to make choices (CC, Kingston)."

Choices need to be made freely and without external compulsion. As defined by one committee member, choice means "no one is picking for you, it's yourself and not someone else (CC, Toronto)." Choices made with too much external support may be reflective of the goals of family members, staff and support agencies, rather than those of the individual (Finlay et al., 2008; Kearney & McKnight, 1997; Stancliffe & Abery, 1997; Stancliffe, 2001; Wiltz, 2007). At the same time, autonomy in choice making does not preclude the support of others. Support staff can be an excellent resource to help persons with IDD make informed choices: "[staff can help individuals make choice by] going over the pros and cons of the different options, and listen to [individuals] while they work through the options (CC, Thunder Bay)," and "counsellors can help, get information, but then let the person make the decision (CC, Toronto)." Furthermore, choice occurs in the context of interpersonal relationships, and so it is quite reasonable for individual choices to involve the input of other people (Barron, 2001; Fyson & Kitson, 2007; Ho, 2008; Katz & Assor, 2007; Schloss, Alper, & Jayne, 1993; Sinding & Wiernikowski, 2009). The challenge in promoting choice is maintaining the balance between too little external support and too much external control. The appropriate level of support will depend on both the person choosing and the specific choice being made. Consumer committee members highlighted this need for balance: “Sometimes you get more help than you really want or need to make a choice on your own (CC, Kingston).”

Component 4: Choice Requires a Supportive Environment

For persons with IDD, an unsupportive environment may result in diminished motivation to choose, or a belief that they are not entitled to choices (Brown & Brown, 2009; Harris, 2003). To overcome this, the environment needs to explicitly encourage choice and provide feedback that allows individuals to learn from their choice experiences (Bambara, 2004; Fraenkel & McGraw, 2007; Harris, 2003; Lancioni et al., 1996; Stalker & Harris, 1998). Choice opportunities for persons with IDD may be limited out of attempts by staff members and family to protect individuals from the potentially negative consequences of choosing, such as regret or distress. Staff members also struggle to balance the provision of choice with their responsibility to care (Barron, 2001; Finlay et al., 2008; Guess et al., 2008; Ogden, Daniells, & Barnett, 2009; Schloss et al., 1993; Stalker & Harris, 1998). Respecting choice means recognizing that it entails an element of risk. While restrictions on choice may be justifiable if the risks endanger individuals, in most situations, experiencing the consequences of choice, whether they be positive or negative, can build individuals’ sense of dignity and autonomy (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Barron, 2001; Guess et al., 2008). Several members of our advisory and consumer committees discussed the importance of experiencing the risks associated with choice: “There is a certain dignity of risk. We need to give people the dignity of making choices where choices are risky (LAC, Toronto),” and “If you’re making bad choices, they should let you try it once so you can personally decide to stop (CC, Toronto).” Experiencing choice and the risks that go along with it provides persons with IDD with valuable learning experiences that can significantly shape their future choices. This was highlighted by a consumer committee member: “how else can we learn? (CC, Toronto)” and a local advisory committee member:

“Let’s say I want to spend time with somebody and my parents don’t support the decision. I still want to make the choice, and maybe my parents can step in if I start to get hurt. But let me choose the first time. Let me have that opportunity to try, to see and learn that it isn’t working for me (LAC, Toronto).”

Discussion

The freedom to make choices has historically been limited for persons with IDD, largely as a result of institutionalization and exclusionary practices. In the past decades, significant steps have been taken to move towards a model of services and supports in which persons with IDD make choices and have greater say in their everyday lives. In Ontario, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2008), identified choice as an essential service outcome. Service agencies must demonstrate their success in promoting choice, and doing so requires a practical definition of choice that lends itself to implementation and measurement.

We identified four components of choice that are recurrent across the literature and necessary for choice to occur. Choice requires opportunities, which are the occasions in day-to-day life where choices can be made. Choice also requires a broad number of options, which are the alternatives available to individuals and from which they can select. Choice involves the cognitive evaluation of the available options and the observable act of selecting an option. These steps need to be informed by an understanding of the options, and occur autonomously, with the appropriate level of support. Finally, choice requires a supportive environment that recognizes the risks and benefits of choice and proactively supports individual choice.

When monitoring the success of services in promoting choice-making in persons with IDD, it is therefore important to assess the availability and diversity of choice opportunities and choice options, as well as the information and supports provided to individuals to make an informed and autonomous choice. A significant challenge in promoting choice-making in persons with IDD arises from the need to respect the right of persons with IDD to autonomous choices and their associated risks, while at the same time balancing it with competing demands. Persons with IDD and service providers from our consultation groups have highlighted tensions between two sets of values that guide service provision: the promotion of the freedom to choose and the desire to protect a vulnerable group from harm. In Ontario (and many other jurisdictions that have similar policies), government-funded services supporting adults with IDD must demonstrate their compliance with safeguarding policies. Although choice promotion is stated as an important policy objective, quality assurance measures provide very little opportunities to monitor the success of services in reaching that goal. Using indicators of quality of services that do not represent all organizational and policy objectives likely incentivizes performance on objectives that do not reflect the desired goals (Poister, 2010). As such, assessing compliance with measures to protect persons with IDD without monitoring efforts to promote choice leads service providers to prioritize the former set of values to the detriment of the latter.

Rekindling the Ideology of Choice

With a lack of practical definitions, choice for persons with IDD may be viewed more as an ideology rather than an achievable outcome with evidence of the “right thing(s) to do” to promote choices. An ideology is a system of ideas, beliefs and values held by an individual or group and which inform behaviour and actions (Brown, 2012). While ideology can help us focus on the things that we think are most important, it can also be detrimental when it drives policy development without sufficient consideration of how the policies will be implemented (Brown, 2012). Previous research on choice has been largely theoretical and not informative to planners and providers who are tasked with developing, implementing, and evaluating services that are supportive of individual choice.

This review represents a step towards the development of a practical understanding of choice that informs service development and evaluation, as it provides a description of the components of the experience of choice that should be monitored to inform quality improvement across IDD services. However, more work is needed. A crucial issue that needs further consideration is how services can demonstrate their accountability in promoting choice among the persons they support. While choice is a right of all persons with IDD, efforts to promote choice must be balanced by consideration of individual abilities and limitations, as well as the relationships and social structures within which persons with IDD are making choices (Fyson & Cromby, 2013). Therefore, a “one size fits all” approach to evaluating service providers’ efforts in promoting choice is not appropriate. Such an assessment must take into account the fit between the individual and the services provided.

In addition, this review highlights a significant tension that exists between the recognition of choice as a valuable service outcome for persons with IDD, and the practical implementation of these policies by service providers. IDD service providers have a responsibility to protect this vulnerable group from harm. At the same time, service providers must support choice in persons with IDD, even though choice may bring negative consequences to the chooser. As IDD policy shifts to emphasize choice as a required service outcome, support staff will likely struggle to balance these two competing agendas.

Study Strengths and Weaknesses

This scoping review had several strengths. Both authors reviewed the summaries of the articles included in the review, and the content discussed in order to reach a consensus on the core components of choice. The results of the scoping review are further supported through our discussions with consumer and advisory committees from across Ontario, which include persons with IDD, family members, as well as service providers. A multidisciplinary team of researchers with extensive experience in the fields of IDD and policy also provided feedback in the development of this paper.

This paper has several limitations that should be noted. We did not conduct a systematic review of the literature, but rather carried out the literature review until saturation was reached. We did not conduct a search of the grey literature, as is sometimes done in scoping reviews. The data from the consumer and advisory committees were not formally sought through appropriate qualitative methods, such as member checking and saturation.

Conclusion

Evidence of the "right things to do" when promoting choice among persons with IDD is limited. Service providers in Ontario, operating under the new *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2008), are ill-equipped to develop services that promote choice. Further work is needed to help service providers evaluate their services to demonstrate accountability, and maintain a balance between promoting choice and protecting this vulnerable group from harm.

Key Messages From This Article

People with disabilities: You have the right to make choices. While support staff can help you make choices, it is important that they listen so that you are able to make the choice you want to make.

Professionals: A supportive environment that values and promotes choice will greatly benefit persons with IDD. However, choice often involves risks and consequences for the chooser. You may experience conflict between the desire to protect from harm and the wish to respect choice.

Policymakers: Identifying choice as a service outcome for persons with IDD is a welcome shift in policy. Further work is needed to define choice in a practical way that can be used in service development and evaluation.

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