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An International Conversation on Disabled Children's Childhoods: Theory, Ethics and Methods

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Abstract

This article brings together members of the International Advisory Committee for the Inclusive Early Childhood Service System (IECSS) project, a longitudinal study of interactions with institutional processes when families have a young child with disabilities. The article introduces international discourses on early childhood development (both individual and community) and raises questions about the ethics of these discourses in the context of historical and current global inequalities. We consider the exporting of professional discourses from the global north to the global south through directives from global institutions, and the imposition of medical thinking onto the lives of disabled children. We discuss theoretical positions and research methods that we believe may open up possibilities for change.

Keywords

Disabled Childhood Studies, Institutional Ethnography, Early Childhood, Sustainability Goals, International Development

Introduction

This article brings together members of the International Advisory Committee for the Inclusive Early Childhood Service System (IECSS) project. IECSS is a longitudinal study of interactions with institutional processes that families experience when they have a young disabled child. The IECSS International Advisory Committee has engaged in an initial discussion about interpretation of the IECSS findings, and both the limitations and possibilities of sharing research across varied and geo-political contexts. As part of the work of the Advisory Committee, we have been contemplating the research methods of the IECSS project as a possibility for understanding systemic issues of interest to disabled children and their families in different geo-political contexts, as well as for the families who are participating in the ongoing research of IECSS. The Committee came together sharing a commitment to an approach that fully supports disabled children's childhoods by understanding their experiences and aspirations in context and taking a critical approach towards any imperial claim that science by its own definition has universal applicability that we continue to see featured in both child development and international development (Goodley & Runswick-Cole, 2015; Grech, 2013).

This article presents some of the conversations that have been unfolding amongst the members of the Advisory Committee. We (the authors) are academics committed to thinking about disabled children's lives as a point of interest for all of us. Our interests are in promoting ways of thinking about, and engaging with, disabled children that value them as members of their communities and that see their experiences and viewpoints as important for understanding international development. Further, our interests are in international development discourses that are focused on early childhood, education or early intervention. We aim to ask research questions that go beyond documenting disabled children, toward approaches that can elucidate the power

imbalances that are entrenched in institutional practices, and that allow us to document the ways that dominant discourses impose themselves on the lives of disabled children (Ineese-Nash et al., 2017). We therefore share a commitment to approaches that engage with social oppression. Discussions of children's lives are, too often, framed with reference to their failure to match up to the mythical norms of child development (Burman, 2008). As a Committee, we fully support a tradition of research and scholarship that seeks to challenge representations of disabled children's childhoods as being tragic or lacking and celebrate the potential of all children's lives (Connors & Stalker, 2007; Curran & Runswick-Cole, 2014; Shakespeare & Watson, 1998).

Our call to focus on the lived realities of disabled children's lives is, in some ways, nothing new. Back in 1999, Watson et al. exhorted childhood researchers to move away from a focus on "impairment, vulnerability and service use" (p. 2) and yet, a social oppression model of disability has struggled to make an impact on the mainstream childhood research agenda. While disability studies scholars have paid attention to the disabling barriers in children's lives (Greenstein, 2015; Goodley & Runswick-Cole, 2010, 2011, 2012; McLaughlin et al., 2008; Read et al., 2006; Slater, 2015), studies of childhood disability remain an adult-centric area of study that has frequently ignored the lives of disabled children (Wells, 2018).

We suggest that there are two reasons for this:

- 1) Disabled children trouble the foundational principles of the new sociology of childhood (James et al., 1998) which depend on a characterization of children as bounded, independent rational and active social agents in their social worlds. Disabled children, and others who cannot conform to this account of agency, have become a 'problem' for childhood studies which has led to disabled children being marginalised or ignored within theory and research practices (Wells, 2018).

2) While childhood studies has accepted that childhood is socially constructed in its historical and temporal location, disability has been excluded from the social constructionist turn and the ‘norms’ of child development continue to provide a rationale for segregated or ‘special’ welfare and education provision in the lives of disabled children and the exclusion of disabled children from research (Burman, 2008).

Our Dialogue

Research narrowed to a focus based on impairments produces a deficit myth of autonomy and independence that creates vulnerability and barriers. The authors of this paper seek out research that is the impetus for creativity and activism that is generating resistance and holds a very different focus. Discussions about disabled children’s lives have, however, been dominated by scholars from a narrow geographic location, leaving out perspectives that recognize both majority and minority viewpoints (Ali et al., 2001). Our goal in sharing the conversations unfolding amongst this group over several years and solidifying the creation of the International Advisory group is not to suggest that the theories to which we ascribe should be adopted in local contexts, but to contribute to global discourses that position childhood in relation to medicalized rehabilitation, a focus that is pervasive in international development discourse.

The discussion that is unfolding between the authors, and which we present in this article, is a representation of actual conversations that have taken place between International Advisory Committee members. This conversation began when Marisol Angarita Moreno, Kathryn Underwood and Don Wertlieb began talking at the International Society on Early Intervention conference in Stockholm, Sweden in June of 2016. Marisol, an academic from Bogota, Colombia had seen Kathryn present on the first phases of the IECSS project at the conference (Underwood

& Frankel, 2016). Marisol was interested in the methods and the possibility of their application in a similar project in Colombia. Our discussion emerged when Marisol identified that the approach used in the IECSS project was of value both to her work and to work she had been doing with international organizations, especially the Early Childhood Development Task Force (ECDtf) in partnership with Donald Wertlieb. Marisol was interested in how the methods used in IECSS might be adapted or translated to her local context, in order to better understand how theories of disabled childhoods can be hidden in the procedural environment of NGOs, service organisations and developmental institutions. Don's work contributed a global perspective with his extensive experience in working with international scholars and organizations that are inclusive of the youngest children, including infants and toddlers, and connecting their interests to a global development agenda that is grounded in the Social Development Goals (SDGs), discussed further below (United Nations, 2015).

We were interested in the possibilities to change how global institutions take up childhood disability that might arise from changing the theoretical positioning of disabled childhood, and the research methods that might enact a more progressive agenda in international frameworks. For this reason, we sought the expertise of Tillie Curran and Katherine Runswick-Cole who contribute their work and experience with disabled children's childhood studies. Tillie and Katherine had likewise become part of the conversation through their interest in the IECSS research and Don's leadership on a Global network for disabled childhoods at the ACEI Global Summit on Childhood 2014 in Vancouver, Canada.

Our collaboration as an International Advisory group led to a symposium presented at the European Academy of Childhood Disability (EACD) in Paris, France, in May 2019, where we began to ground the dialogue that is in this paper (Underwood, Wertlieb, Curran, Runswick-

Cole, Moreno-Angarita, 2019). The conference provided a venue where the majority of researchers are situated in a medicalized discourse and where the goal is to “scale up” rehabilitation and intervention services to reach the largest number of impaired children globally. Our goal was to introduce ideas that might disrupt normalized ways of thinking about disabled childhoods. We were surprised at the pervasiveness of the messaging at the conference, that services need to be clinical without opportunity for open ethical debate on universalist methods. We found that our view of a pressing need for change driven by participation and community that we were working on and promoting (see edited international collection of disabled children’s childhood studies Runswick-Cole et al., 2018) was absent from the developmental discourse. This, however, is not a fixed or inevitable situation. The mini symposium we presented was full and the discussion revealed a significant interest in the roles of mothers and fathers, the challenges new parents face, and how an ontological shift from studying children and their families, to studying the assumptions that are hidden in the procedural and institutional environments that produce childhood disability might create new conversations. This article arises from our reflection on our experience at the conference and is a snapshot of our discussion up to this point.

A key question that arose for us is the ethics of transferring research findings from wealthy nations (including Canada, the UK and the US) to countries that are described in global discourses as low and middle-income countries (LMIC), or the global south (Chataika & McKenzie, 2016; McKenzie & Chataika, 2018). As other scholars have noted, there has been a lack of understanding about the role that disability plays in international development discourses, especially where disability has been a focus. Further, these initiatives have reinforced colonial

relationships with NGOs, and concern about access and control for local populations over their own service systems (Chataika & McKenzie, 2016).

In this era of globalization, there is ongoing interest in how collective action can lead to equalization of opportunity through investment in economic and social development. An example of this type of investment is the promotion of scientific knowledge to a global audience as the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Disabled Persons (CRPD) are implemented across global contexts. The directives are rooted in human rights frameworks but many of them are also focused on rehabilitation services and research that is premised on the idea that disability is a medical condition that needs to be fixed. In this presentation of our discussions, we introduce some of the international directives that seek to draw attention to the need for economic, social and political investment in the lives of disabled children. We then examine the concerns that arise in implementation of these frameworks. We share our conversations in the spirit of laying bare our theoretical and methodological positions that challenge approaches that are deeply entrenched in the societies in which each of us lives.

An important part of our focus is how disabled children's lives, especially the youngest children's lives are represented in this international agenda. We are interested in challenging international development discourses from organisations such as UNICEF, the World Health Organisation, and the United Nations, that focus on inclusion and human development to the exclusion of other agendas.

We see the tensions between children's rights as participants in decision making about them, and the adult world, which is seeking to develop accessible services. We recognize disability as an identity, and at the same time the importance of ensuring access to service.

Rehabilitation has value but it is also a theoretical framework that has implications for children and families in the ways in which policies are implemented.

We see a need to more broadly understand the social construction of disability in a local context and the intersectional oppressions that affect service delivery. Simply because a service is available does not mean that it is equally accessible to all children and their families (Magana et al., 2019). To that end, research methods that capture these variables are recommended for ethical implementation of services and to ensure that scaling up of services systems globally does not lead to further marginalization of disabled children and their families.

International Development Frameworks

As our conversations unfolded, the authors of this paper were involved with other initiatives that aimed at ensuring better access to services in what are now called low- and middle-income countries (LMICs) (The Lancet, 2016). This term captures what are in fact countries that are primarily in the southern parts of the globe, they often have histories of colonisation, and have indigenous populations that are frequently not well represented in government. Yet little of this political history is evident in the directives for development of service systems that are inclusive of young disabled children, in the international developmental discourses (Chataika & McKenzie, 2016).

International frameworks for development in LMIC are focused on better access to services for disabled children and their families. Our interest is in how we can shift from governing ideas such as evidence-based practice that is restricted to “gold-standard” and “new science” principals (i.e. clinical research that narrowly focuses on developmental outcomes) to the exclusion of work that has a broader social and aspirational mandate. We believe this should

be inclusive of children, young people and families and recognize that disability “stigma” is intersectional with other forms of discrimination. Further, we would like to recognize that the global south has a contribution to make that is often excluded via linguistic, economic and cultural barriers from the canon of acceptable research that informs international frameworks. Grech (2013), for instance, points to the impact of normative research for disabled children and their families in Guatemala, suggesting that funding needs to be informed by family and community ways of living. A recent systematic review of stigma-reduction interventions in LMIC illustrates some of these opportunities and challenges that arise from research that is linked to local contexts (Smythe et al., 2020).

At the same time, we are aware of the privilege that is held in a position that values human difference. As others have noted, impairment and poverty are inextricably linked across the globe with poverty being the most prevalent underlying cause of impairment and its social counterpart, disability (Dirth & Adams, 2019; Stone, 1999). Poverty of course cannot be detached from colonisation, globalisation, climate change and inequality. We are interested in any approaches that break the cycle of authority that comes from narrowly defined theory and research approaches which determine how bodies should function, what they are capable of and which roles they should play. We also recognize that the theory and research approaches we present in this article are examples of mechanisms for disruption, but there are many theoretical and methodological approaches from around the globe that might do the same.

In 2015, the United Nations introduced a governing framework for international development in the form of 17 goals for global development between 2015 and 2030. Of interest in these new Sustainable Development Goals (SDGs) is the simultaneous focus on the interdependence of the goals and the actions that are a result of the SDGs. Several key features of

the international development discourse are repeated and warrant further consideration. These include the importance of the first 1000 days in the life of a child, the need to scale-up services, prevalence rates of impairment as evidence of deprivation, and the promotion of rehabilitation services. While each of these constructs is rooted in science, they can also create risk in application if they do not take into consideration the relational contexts of children, their families, and their communities. To that end, multiple avenues and platforms for such activities have been articulated in international discourses with an emphasis on a rights-based framework for inclusion of young children with disabilities and their families (Wertlieb, 2018). For example, International frameworks like the World Health Organization (WHO) (2018, 2020) Nurturing Care Framework provide an opportunity, or an opening, to consider the social, political and relational contexts of children and their communities. However, even documents with goals of being more sensitive to a social and political discourse become problematic when implemented in ways that perpetuate discrimination. This happens through narrowly defining which life stages are the most important, by scaling up the local as a standard rather than standardizing international initiatives to make room for the local, and by valuing rehabilitation services above all other services. For example, the Nurturing Care Framework says,

Childhood disabilities impose a huge emotional and economic burden on the affected families and children. Caring for children with disabling conditions is demanding, especially in places with inadequate infrastructure and access to services and support. Unfortunately, families often face many challenges and disadvantages. These include living in settings with inadequate access to good-quality early identification, inadequate referral to early childhood intervention services, and inadequate support for caregivers and family. Families may also lack financial resources, and they may face environmental

barriers, discrimination and social exclusion, as well as stigma from society and providers (WHO, 2018).

Missing from this statement is recognition of the underlying conditions of poverty. Disability is both a cause and effect of poverty as well as a key consideration in addressing adversities such as violence, climate change, and forced migration (Lombardi, 2018; Olusanya et al., 2018; Richter, 2018). In addition, the very notion of disability in the statement above is premised on medical conditions located within the individual rather than in the socio-political context. In order to shift this viewpoint, we feel it is critical to consider a different theoretical orientation to disability itself. Care for disabled children is positioned as an unwelcome ‘burden’ on families, and, implicitly, on the state—a far cry from the UN rights and expectations that the state is responsible for protecting those rights. We believe this to be a more ethical stance, and our theoretical and methodological approaches aim to put these values into action.

There is a growing focus on access to service, with reference to the strong science behind rehabilitation and intervention approaches (The Lancet, 2016), but there is a dearth of research and focus about the complexity of disability and identity in global development discourses. Disabled children’s experiences of disability are part of a socially constructed reality that is embedded in the very services that international development is calling on to be scaled up. Our position is not that rehabilitation has no value, after all it is a right (CRPD, Article 26). However, the practice and organization of rehabilitation is premised on theoretical positions that have been developed through Western medicine with serious ethical implications for the exporting of social policy and directives from countries where medical models continue to be widely embedded in service systems.

The Inclusive Early Childhood Service System Project

The Inclusive Early Childhood Service System (IECSS) project seeks to understand the institutional interactions of families who have young disabled children. The study begins with the premise that understanding families' earliest experiences with early childhood services helps us as a society to understand the construction of some children as disabled. Through annual interviews with families over a 6-year period our ultimate goal is to better understand how families are being organized through early childhood education, care and intervention systems.

Our goal in this research is not to study impairment or the efficacy of particular interventions. Instead, our intention is to understand institutional cultures and practices from the standpoint of families. Through partnership with local community organisations starting in 2013, we found an interest in better understanding how early childhood and intervention systems hold power and construct disability. Once we had begun interviews, we identified a fit with an approach called Institutional ethnography (IE) that helped us to respond to the questions being asked in communities. IE is concerned with how "ruling relations" shape everyday lives. Ruling relations are the administrative, managerial, professional, and discursive organization of regulations, and the governing structures of a society (Smith, 2006, 2009). This method is evolving as it is used in different geo-political contexts (Parada et al., 2020). In our study, family experience becomes the informant about how institutions and policies, including those from global agendas, are actually happening on the ground. This approach can add to work that analyses the theoretical position of policy itself (Okeyo et al., 2020).

Through our annual interviews, we are mapping the social relations that are evident in the work that families do to access and maintain relationships with services. This institutional mapping examines the ideology behind the institution, and the processes that are in place to do

the work of the institution. Our aim is to provide empirical evidence of the ideology, the processes, and the social relations (Grahame, 1998) through documenting the work of families as they interact with early intervention and education. Fundamental to the approach is mapping the actual activities of the institution (Campbell & Gregor, 2008). Ultimately, our goal is to inform social policy, and theoretical understanding of childhood through the experience of disabled children and their families. Our work, which uses families as informants, aims to create a more complex discourse of disabled early childhoods that is grounded in recognition of the value of diverse childhoods.

Through our method, we believe we have empirical support for the following key findings:

1. How do the institutions work/hold power?

The system works because families and mothers in particular are doing much of the work, and this work is gendered. The institutions have processes that families and frontline workers must comply with in order to gain and maintain access. The institution holds power by creating a textual record of disability and by governing the actions of families, children and workers through procedural and managerial actions. Most discourse on childhood disability centres on gaining access to services (Underwood, Frankel, Parekh & Janus, 2019; Underwood, Smith & Martin, 2018).

2. What processes lead to action in the system?

The early intervention system operates on a medical model that is deeply entrenched. The system of services for young disabled children is predicated on a medical model, which makes diagnosis or designation of disability central to how the system works. This approach is not consistent with many cultural viewpoints regarding disability and is used as a

gatekeeper for services that may be central to inclusion and quality of early learning and childcare for disabled children. A theory of disability matters. Often, a theory of disability is operating as a meta-text: a professional discourse that is taken for granted.

3. What do families contribute to the system?

The more services a family has, the more the system needs from them (time, money, energy, relationships, etc.). Accessing disability supports and services is a lot of work for families. Family members become responsible for “normal” development, in a series of requirements on the part of institutions to simultaneously act as advocates for their children and to comply with the structural requirements of programs. Families are making continual micro-decisions to comply or to resist the power of the state (Underwood, Church & van Rhijn, 2020).

Disability justice requires recognition of the complex identities, communities and intersectional oppressions that children and their families experience in their daily interactions (Berne, 2015). This means that attention must be paid to colonialism, racial and ethnic status and discrimination, gender, economic disparity, geographic and political contexts (Underwood, Ineese-Nash & Haché, 2019). Disability justice gives a different understanding of how families are positioned in their contributions to the system.

The presence of disabled children often creates disruptions that change how people do things and how people relate to each other. IECSS has drawn on theory from disabled children’s childhood studies, which welcomes these moments of disruption as desirable and potentially beneficial. Disability as an opportunity or invitation for change can lead to disruption of norms and assumptions that are beneficial to all children (Goodley & Runswick-Cole, 2015; Goodley et al., 2015). The experience of families accessing service systems organised around disabled early

childhood offers very real potential to better understand how the organising of children, early childhood education and care services, and early intervention services is experienced. Further, while we began with disabled children's childhood studies as our theoretical framework, the method has been taken up with partners who hold their own theories of childhood and disability (Underwood, Ineese-Nash & Haché, 2019).

Disabled children's childhood studies calls on researchers to include disabled children in studies about their lives. However, our focus on institutionally produced and procedurally driven activities for the youngest children requires us to situate family members who are decision makers as our informants in understanding this system. At the same time, we have sought the expertise of disabled and deaf youth to help us interpret these findings through the activities of our Youth Advisory Committee (Snoddon & Underwood, 2019; Underwood & Atwal, 2019). We hope that this approach allows us to be present in exciting new areas of research that position disabled children and youth as central to understanding disabled childhoods (Liddiard et al., n.d.).

What the research contributes to the international discourse:

There are some basic assumptions that are evident in international development, human rights and rehabilitation discourses. These assumptions are challenged by what we have learned through the IECSS project (Underwood, Frankel, Spalding & Brophy, 2018).

Assumption 1: More service is always better.

Assumption 2: The relationship with institutions is neutral.

The logic model thinking that positions children and families as the neutral recipients of service does not account for the work of families, and the resources that are taken from families, to access services.

Assumption 3: Disability equals service “need”.

Most research looks for child level outcomes, especially developmental gains. This is how the “gold standard” for evidence is established. However, not all disabled children need services, and in particular, categories of disability should not be used to determine “need”. For example, all autistic children do not need behavior intervention.

Assumption 4: Access to service lessens risk.

IE provides a way to study the risks to families of engaging with institutions. We see that families who have precarious custodial or citizenship status, who have precarious housing or low food security are more at risk. Interactions with rehabilitation services can lead to surveillance, which disproportionately affects communities who are already at risk for their children being taken into child protection systems. For example, in Canada, we have learned this includes families who are members of Indigenous communities, and families experiencing poverty.

Implications for global conversations continued

In our discussions, we continue to be aware that most of us are from global minority countries and our theories and methods are developed in that context. As described above, the conversations about internationalisation of theory and methods, began with the question of whether approaches from the IECSS project would be useful when applied to work in Colombia. Our conversations now turn to whether the approaches presented in this article might be useful in decolonising and developing locally relevant and situated understandings of disabled children’s lives and aspirations. First, we recognize that disability, disabled childhoods and services have

different meanings in different parts of the world, and therefore, knowledges in local contexts necessarily must inform all research and service planning. In the IECSS project, our ontology is focused on studying social systems, but the project has been intentional in ensuring that community partners, particularly Indigenous partners, have been leaders in the design, implementation and analysis of research. In fact, while the methods of the project are derived from the Institutional Ethnography literature, the procedures are unique to this project because they have been in response to community partner directives and local Indigenous Wisdom Keepers (Underwood, Ineese-Nash & Haché, 2018). We also recognize that if the theories and methods that we have described are undertaken in other contexts, paradigmatic shifts will result because the theory and methods themselves are dynamic and will be influenced by disabled children, their families, and local knowledges. As a result of these types of shifts, childhood studies as well as international development objectives must recognize themselves as fields in constant development. This has implications for services, research, training and professional development, especially in LMIC, where this is a relatively new project.

Disability studies in the global south tends to polarise rehabilitation services against the social model (Balcazar et al., 2018), creating tensions between disabled people and the services that are meant to support them. We argue that there may be a different way forward, with recognition of the right to services, but with resistance to defining children by the services they access. To critique the social organisation of services and the power of these institutions will differ between nation states and across geographies. These geographies are partly defined by political boundaries, but we also know that rural, urban, and remote communities have very different access to services and that the political and social power that is held by communities impacts the privilege that individuals have to self-determination, including aligning with

impairment specific communities. For these reasons, we find hope in theoretical and methodological approaches that see disabled childhoods as valued and that understand the experiences of disabled children and their families as an important source of knowledge for understanding how international development initiatives hold power in local contexts.

The international influence of the Convention on the Rights of Persons with Disabilities (United Nations, 2007) and the SDGs should not be undervalued; for example, in Colombia and other countries in the Latin American region, without these frameworks, some advances in access to services would have been impossible. The international frameworks mentioned above have made visible the dignity of disabled people and have promoted a generation of disabled children with much greater recognition of their value in societies than in previous generations (Moreno-Angarita, 2011). However, other international discourses, such as disabled children's childhood studies, and research methods that shift the ontological project toward understanding institutional power, can also positively influence local contexts and in turn be positively influenced by engagement across global discourses. Celebrating disabled children's childhoods has strong resonance in the global south to change and promote disabled identities consistent with local activism.

Until this point, impairment, intervention and the discourses of health, education and rehabilitation have been dominant in development discourse. The social model of disability has been named but we continue to need conversations that clarify how this theoretical position, and more specifically disabled children's childhood studies, can change the organisation of professionals and policy. To date there have been many misuses, abuses and misunderstandings about the social model, resulting in a lack of shared understanding or comprehensive application of theory or approaches that are grounded in the lives of disabled children in Latin America. The

methods identified in the IECSS project, in conjunction with disabled children's childhood studies, provide a possibility for "evidence based on experiences." This is a new epistemological perspective for understanding disabled children's lives that resonates with the work Marisol and her colleagues have been doing in Colombia (Magana et al., 2019).

Concluding questions

We offer the following questions as a concluding set of ideas that guide our work, and for others to consider as they work across nations, cultures, languages and identity groups. Perhaps more importantly we hope that disabled children may provide us with some answers to these ideas as they contribute to our growing understanding of diverse childhoods (Liddiard et al., n.d.; Snoddon & Underwood, 2019; Underwood & Atwal, 2019).

- How does a theory of disability shift focus toward full, productive childhoods and futures? How do different worldviews contribute to and get listened to in international or global conversations?
- How can particular research methods shift the focus towards evaluation of institutions rather than evaluation of the child? Are the methods used in our own research of value in international discussions?
- How might policy and services be re-imagined and organised to support disabled children's childhoods and their aspirations? Do the methodological approaches proposed in this article help this re-visioning, or do they further centre global north discourses? Is there value in continuing to engage across global north/south conversations?

- How can we listen to disabled young people and their families to understand their context and intersectional oppressions so we can make policy and services much more relevant and accessible?

Future work of the International Advisory Committee and of the IECSS project will focus on these questions and will aim to engage with scholars who can expand the position from which we ask and answer these questions.

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