Including as a Care-ful Journey: A Parent's Perspective

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The authors argue for the need of a cyclical, rather than a linear, model of family coping and life management when a child has a disability. Longitudinal support for such a cyclical model of family life management is presented, with recognition that parental control of outcome lessens as the young person ages, because the adult world is not inclusive. In presenting longitudinal support from a single case study, attention is drawn to the importance of a societal response of inclusion and caring, especially as a child exits educational programming and transitions into adulthood in a non-inclusive world.

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The purpose of the paper is, first, to examine support for a cyclical, rather than a linear, model of family coping and life management when a child has a disability, presenting the authors' own cyclical model of life management (e.g., Scorgie, Wilgosh, & Sobsey, 2004) to demonstrate usefulness over time of such a cyclical model, using illustrative data from a single longitudinal case study. The second thrust of the paper follows from the first and the related case study data, namely, examining the transition from the child's educational years into early adulthood, and the prospect for social and vocational inclusion of young people with disabilities in a society that is, in many ways, non-inclusive.

Many studies of family coping following diagnosis of a disability in a child have utilized linear models of coping with loss, with parent and family functioning measured along a number of stages from denial to adaptation or acceptance (Muscott, 2002; Roll-Pettersson, 2001). However, in a mixed method study of stress and coping in 63 mothers of children with autism, O'Brien (2007) concluded, "Even today, despite all the empirical work showing that 'grief work' is not effective in helping people cope with traumatic loss . . . many professionals who work with families of children with disabilities expect parents to progress through grief stages" (p. 145). O'Brien even questioned whether focusing on resolution or adaptation as a measure of coping was useful ("Another common belief… is that psychologically healthy parents will eventually achieve resolution… " [p. 145]), given the many unknown child and family variables parents of children with disabilities must contend with over time. Therefore, expecting that all families will respond to the diagnosis of disability in a child according to a set of prescribed stages, O'Brien purported, is unrealistic. Thus, there is increasing support for exploring alternate approaches to parent and family coping following diagnosis of disability in a child (O'Brien, 2007; Roll-Pettersson, 2001; Taunt & Hastings, 2002).

Some researchers suggest that coping has been too often explored through single data gatherings that represent family functioning as a single snapshot in time. Because coping is increasingly being understood as a process across time, with corresponding ebb and flow, there has been a call for a more developmental examination of family coping, taking into consideration movement across various child and family developmental markers (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Kuhn & Carter, 2006; Lazarus, 2006). Lazarus (2006) suggested that, in order to study coping as a process, researchers need to " . . . seek rich in-depth descriptions of the lives of individuals over time and diverse conditions" (p. 42). Therefore, longitudinal research designs that situate an individual or family within an environment or context and that incorporate dynamics of change across time are essential to the study of coping (Harry, 2002).

Recent research on family coping following diagnosis of disability in a child has also been shifting from a focus on family stress to an examination of those variables that enable families to function effectively amid the added stresses (Risdal & Singer, 2004; Scorgie & Wilgosh, 2008). Researchers have examined such parent and family coping variables as locus of control, agency, and social support as key to family outcome (Dellve et al., 2006; Hintermair, 2004; Horton & Wallander, 2001, Kuhn & Carter, 2006; Twoy, Connolly, & Novak, 2007). As a result, parents are urged to become empowered advocates for their children. According to Hartshorne (2002), "Parents with courage will seek out services for their child and push medical and educational institutions to provide what the parents believe their child requires" (p. 269).

In addition, there has been greater interest in moving beyond focusing on individual families as coping entities, to exploring the larger societal constructs in which families are situated, which have a strong effect on family functioning. For example, Green (2007) argues that research on parenting children with disabilities has overemphasized the emotional distress experienced by parents, while largely ignoring the socio-cultural constraints encountered by families that are the underlying cause of much of the emotional distress. In a quantitative study of 81 mothers of children with disabilities, she found a high correlation between perceived stigma (i.e., the belief that society devalues persons with disability) and emotional stress. Parental stress, she argues, may be heightened when parents perceive societal limitations on the range of child and family outcomes. Similarly, in an earlier qualitative study of eight persons with disabilities and seven mothers of children with disabilities, Green and colleagues (2005) concluded, "The interviewees suggest that the reaction of others can play a primary role in feelings of depression among individuals with disabilities and their families and that this depression can lead to further social isolation [and] status loss . . ." (p. 211). Green et al. purport that, to a large extent, difficulties surrounding disability are situated more in social constructions of disability, that is, in how persons with disability are perceived by and treated in society, than in intra-personal or intra-family variables.

The truth is that the majority of parents of children with disabilities are required to manage the demands of their family lives in the midst of a cultural context which offers little acknowledgement of, or response to, those demands. Hartshorne (2002) suggested that the responsibilities of caring for a child with significant needs can impact on every area of life, requiring vocational flexibility which may affect family income and limit time for recreation and supportive relationships. Gottleib (2002) wrestled with the ethical issues surrounding whether and how workplaces should accommodate the often inordinate responsibilities parents of children with disabilities encounter, such as the plethora of meetings, medical appointments, and unpredictable scheduling demands. He called for "responsive communities" in which support for persons with disabilities and their families is woven into the moral and ethical framework of community, workplace and societal identities; though he readily acknowledged that it would require "massive [and somewhat unrealistic] alterations in our social priorities" (p. 232). At present, he contends, it is left to parents to negotiate multiple demands and wrestle with the ethical dilemmas of where to place boundaries between family and vocation, mindful of the consequences.

Gaventa (2008) discussed the paradox contained within the label, "care-giver;" especially when those who provide care for persons with disabilities are increasingly required to focus on compliance with laws and regulations, and the multi-layered hierarchical systems that often depersonalize both persons with disabilities and their care-providers. He suggested a realignment of priorities, balancing "commitment and compliance," a movement that would empower both the care-givers and the persons for whom they were caring (p. 599). Person-centered programs would place funding largely under the control of those family members, friends, and care-providers, who have both a direct relationship with the client, and the knowledge, skills and motivation to provide optimal care.

Thus, the trajectory of research in family coping when a child has a disability has been moving from a focus on families as primary agents of coping to viewing the family as situated within a larger societal framework, that ascribes meaning to disability and delimits options in ways that may strongly affect family functioning differentially at various

child and family developmental markers. In addition, longitudinal studies may provide a view of family coping that can extend understanding of family life management across time.

Scorgie, Wilgosh, and Sobsey (2004) have proposed a cyclical model of family life management following the diagnosis of disability in a child, that emerges from the need to reconstruct life subsequent to diagnosis. Gottlieb (2002), professor of philosophy and father of a daughter with disability, wrote, " . . . the life of and life with a special needs child is centered on questions both inescapable and unanswerable" (p. 225). According to Scorgie et al., these questions fall into three categories, each of which precipitates a process. The first category involves identity-oriented questions such as: Who is my child and who can he/she become? Who am I as a parent (or are we as a family), and who can I (we) become? What will life be like--now, and in the future? This category of questioning sets in motion the process of Image-making, as parents seek to construct or reconstruct personal, child and family identities that incorporate disability (cf., Green, 2007; Hintermair, 2004). The second question category, which has to do with meanings (e.g., Why did this happen? What does it mean, both personally and globally?), triggers the process of Meaning-making, as parents seek to construct a coherent understanding of the diagnosis, why it happened and how it integrates into a broader understanding of the world and how it works (cf., Dellve et al., 2006; Gottleib, 2002). The third question category stems from the need to make both immediate and longer term decisions for the child and family (e.g., How should I/we respond? What options are available to us?). These questions trigger the process of Choice-making, as parents explore available options and determine what course of actions will achieve optimum child and family outcomes. Scorgie et al.'s model is appropriate for this study because it enables examination of family life management qualitatively, longitudinally and situated within a social context, not in isolation of that broader context.

Scorgie and Wilgosh (2008) conducted a longitudinal qualitative study of family life management with six parents of children with disabilities across two data collection periods covering a span of ten years. This paper involves a re-examination of data from one case study to illustrate

the utility of the Life Management Process model to explore the ebb and flow of family life management across a number of child and family developmental markers. In addition, the paper will explore the social context as a significant component of image-, meaning-, and choice-making.

Finally, across the past several decades, the emphasis with regard to educating children with disability has been on inclusion, which entails a commitment on the part of educators to locate adaptive resources and services in the general education classroom, rather than placing a student with disability in a segregated setting. Clearly, parents of children with disabilities have been the impetus behind the inclusion movement.   However, many parents have been perplexed when, following successful inclusion in school, they and their children have felt abandoned, left with very few options, as the child transitioned into adulthood. We, therefore, suggest *including* as a term that represents an ongoing responsive attitude and behavior toward supporting and incorporating persons with disabilities in society.

Methodology

Case Study Participant

The criteria for case selection was a parent who had been a participant in the original longitudinal study and whose child had transitioned from public school, that is, K-12 education, to adulthood. Of the six parents involved in the longitudinal study, four met the child transition criteria. Of the four parent interviewees, all mothers, three had also experienced a change in marital status between the first and second data gatherings. Similar transition and family management experiences were shared by all four mothers and their children, all males. Therefore, each of the four participants' narratives contained similar themes.   The case study utilized in this paper was chosen because it most typified the shared themes that emerged from data analysis of all four parents.

 The parent (Diane, pseudonym), mother of Chad (pseudonym), a young person with Down syndrome and hearing loss, was interviewed three

times. The first two interviews were conducted when Chad was 15 years old and Diane was a stay-at-home mother of four children. The third interview was conducted when Chad was 25. In the years between the first two and third interviews, Diane earned a graduate degree, had become divorced from Chad's father, and was employed as a social service worker. Chad had faced a serious illness and hospitalization and was the only child still living at home.

Interview Process and Data Analysis

Following university ethical approval for the larger study, the mother was initially interviewed in a setting of her choice. The parent was asked to present a narrative history (e.g., "Tell me about your family. When did you first discover that [your child] was disabled?"). Further questions explored life management strategies (e.g., "What strategies were helpful at that point? How did you manage…? What personal characteristics were/are essential to effective life management?") and transformational outcomes (e.g., "How have you changed as a result of parenting your child? What have you learned that you might not otherwise have learned?"). The interview was audio-recorded for thematic analysis. A follow-up   interview was conducted several months later by telephone to clarify themes and explore transformational outcomes. Ten years later, essentially the same interview and data analysis procedures were used. (See Scorgie and Wilgosh [2008] for a detailed description of the interview procedures and qualitative data analysis.) For purposes of this paper, data analysis was specific to application of the cyclical model, especially exploring ways in which the processes of image-making, meaning-making, and choice-making were affected by external variables (that is, beyond parent and family) at various developmental markers.

Results and Discussion

Diane began the first interview by describing Chad's birth and subsequent diagnosis of Down syndrome. In her depiction of the event, she conveyed how her first images, meanings and choices were mediated through the powerful lens of health care professionals.   Following

Chad's birth, Diane described being alone in a hospital room waiting to see her newborn son. Eight hours had passed.

> I was told the doctor was examining him, and he should be in shortly. And still he didn't arrive. It seemed like forever . . . And finally the doctor arrived and stood in the door way and said, "There's something wrong with your baby. He's a mongoloid . . . You should give him up. You don't want to ruin your life."

When Diane began to cry, the doctor retorted, "See, he's already ruining your life." The next day, she reported, a social worker came into her room ". . . to tell me that she was there to make arrangements for us to give Chad up." By then the doctor had presented her with a litany of difficulties faced by children with Down syndrome, portraying a fairly bleak picture of eventual child and family life. In the days following Chad's birth, Diane described herself as struggling with questions and emotions. "I was feeling guilty that I had done something wrong in my pregnancy; I was being condemned for some sin that I had committed, you know, before Chad was born . . . that I hadn't been a good mother to [my first child]. I had as many possible things as you can ever imagine."

As she made a determined decision to keep Chad in her room in the hospital, Diane described herself as a "mama tiger. . . I have a stubborn streak in me when I talk about Chad, and I really do believe that that is probably the only thing that got me through." Leaving the hospital with very little information on Down syndrome, Diane said, "We went home and I felt quite isolated." During the first few months her supportive husband "withdrew" as he coped, her extended family was struggling with the news, and close friends began distancing (e.g., "When we told them about Chad, of course they were just devastated . . . our friendship changed after that; they really had a hard time dealing with it . . . we maintained the relationship, but it was different").

When Chad was two months old, Diane was referred to a local organization that supports parents of children with disabilities. A

turning point for Diane was when a mother of a daughter who also had Down syndrome came out to her home.

> And for me it was just—just to see that another family was coping, and that they could laugh and smile about things . . . and it was just like there was a weight lifted off my shoulders. She encouraged me to come to family support meetings. And I came, and I'd see these other moms laughing. It was just like, life goes on. It was a real eye opener for me.

Thus, meeting other parents of children with disabilities and gathering information from books and other resources provided a more positive set of images and meanings for Diane and her family. The choice to enroll Chad in an early intervention program enabled her to acquire skills to begin meeting his needs (e.g., "I felt like I was doing something to make things better"). When Diane realized there were no preschool programs for students with disabilities in the immediate area she took matters into her own hands (e.g., "I was one of the moms who got busy and made sure there was going to be a program"). Chad's preschool days were filled with appointments, interventions, communication therapy, and schooling, all of which were demanding for the family. Diane found herself struggling to place boundaries around the various roles that others wanted her to assume (e.g., "Everyone wanted me to do so many things except be Chad's mom"). Trusting her instincts about what was best for her son and countering the expectations of professionals, Diane began to feel she was being labeled ". . . a difficult parent," a self-image that engendered ambiguity and guilt.

A prominent theme that emerged throughout all interviews with Diane was her ongoing assertion that "disability should not isolate Chad." Therefore, she was determined to provide her son with an inclusive school experience. She became knowledgeable, empowered, and persistent with respect to achieving what she deemed best for Chad. Yet, throughout Chad's school experience, she described having to face the images, meanings, and choices afforded to disability by the external world. Against her wishes, Chad was placed in a segregated program

from Kindergarten through second grade (e.g., "I found that all of the specialists, all the professionals, sort of rallied around and really put large boulders in my path . . . all these people were there to tell me that that wasn't the best placement for him, that I was being irrational and that I was a bad mom"). The resultant stress affected her physically (e.g., "Chad was sick a lot that year, because his mother was sick a lot that year . . . And some mornings I just couldn't get up to take him to school. I just couldn't do it").

Her attempts at inclusion stymied, between grades 2 and 3 the family relocated to another school district that was willing to place Chad in a general education class (e.g., ". . . just in my heart, I believed it was right"). Diane described school success as largely related to teacher attitudes, administrative support, stability of aides, and friendship opportunities with classmates. She summarized Chad's elementary and junior high school years: "It's interesting to watch the pictures of Chad going through the years. You can see Grade 3, 4, 5, and 6 just being incredible growth. Grade 7, the isolation. In the beginning of Grade 8, all the pictures he's alone." She spoke of the difficulty of going through four different teacher aides during seventh grade, which negatively affected access to needed accommodations (e.g., "There were nights when I would be talking to the teaching assistant until 11:30 at night, banging my head against the wall, thinking, 'How am I going to make you understand this?'"). During the same period, support from a local church congregation dwindled with a turnover in leadership and less inclusive attitudes as Chad got older (e.g., ". . . there wasn't the same kind of acceptance, and Sunday school became an issue and we quit going"). Support was found through several friends in the community and an organization serving persons with disabilities and their families. At the end of the first interview sequence, Diane iterated the ways in which parenting Chad had changed her for the better. One theme focused on her work as an advocate for persons with disability (e.g., "I went from seeing myself as not having a lot to give the world, to having a new world—a world of advocacy and friendship"). Thus, Diane had become a determined advocate, not just for her son, but for other families, as well.

During the follow-up interview, Diane picked up the narrative description of Chad's school years. High school, she said, was largely disappointing due to the lack of support for needed accommodations (e.g., " . . . the teachers just could not accept the mindset of modifications and Chad wasn't just going to stop being disabled"). In addition, the high school had a relatively large, "very segregated" special education program for students with disabilities, and Diane felt many teachers insinuated that Chad belonged there (e.g., "There was a lot of animosity towards the fact that we would not allow him to go to that program. . . And I really felt that there was lots of resentment"). After an event occurred during Grade 12, in which a teacher reacted in a harsh manner toward Chad (e.g., ". . . I chose to believe [it] was abusive . . . [Chad] was very distraught . . . but he was not able to articulate that"), Diane removed him from the school (e.g., "We really did end the time that he was there on a very bad note"). While Diane mentioned that several years later " . . . the high school is still not welcoming of inclusion," she still referred to Chad as " . . . a pioneer; I still see him as creating opportunities that wouldn't be there for kids now."

Following public school, Diane was still committed to providing an inclusive environment for Chad. When she discovered that most services for adults with disabilities were in highly segregated settings, she remarked " . . . we just kind of created our own world for Chad." However, with little outside support and very few choices available, Diane realized that she would have to single-handedly find acceptable options. Since high school, Chad had been working several hours a day at a local video store (e.g., "he has a passionate love of movies . . .") and assisting with the recycling program at a nearby office park, all with the help of a full-time support worker (e.g., " . . that's a process, to find the right person, too"). While Diane voiced gratitude for these activities and the kindness of employees, the paucity of meaningful social interactions for Chad within the adult world was, to her, a source of sadness (e.g., "We have done a number of things to invite people into his life; but I find it much more difficult in the adult world than in the school world").

Another source of dismay for Diane came when Chad contracted a serious illness which required several extended hospitalizations (e.g.,

"We very nearly lost him"). Due to mismanagement of his case and what seemed to Diane like low prioritization due to disability (e.g., "We could not leave his side; someone had to be with him at all times. We did not trust that he would get care"), Diane once again was confronted with images and meanings of devaluation (e.g., "And so it was really disheartening to me to see that in Alberta with all of the cutbacks to health . . . just how dangerous it was for one of our kids who have disabilities"). The mother who had earlier described herself as a mama tiger, now referred to herself as a "pit bull."

As a result of the illness, Chad had some significant physical limitations. Two other challenges that Diane described involved Chad's father leaving the home (e.g., "I think . . . he hasn't accepted that Chad is always going to have needs. . . He can't recognize that this is a life-long issue"), and a reduction in her own physical health following an accident (e.g., "I'll be honest; in the past couple of years I haven't had the energy or the ability to do a lot of things; and for a while there I carried a lot of mother-guilt about that one. But I also came to recognize that you can only do so much"). Diane was also coming to realize the limits of parental agency and locus of control, when society was unwilling to accommodate and include.

Diane described Chad as her teacher (e.g., "He is a teacher. He always was a teacher"), and credited him with providing the incentive for her to return to school to earn a graduate degree (e.g., "I have found that I have had such insight and such empathy toward what families have experienced as a result of Chad bringing me up"). She spoke of her life—parenting and supporting her four children, working full time, going through a divorce, dealing with multiple health issues—as being crowded (e.g., "I don't have a lot of extra right now"). As she looked toward the future she spoke of both hope and uncertainty (e.g., "The future is very uncertain for us now"), realizing that, in order for Chad to have a meaningful life, society would need to discover and share her images and meanings of persons with disability, and offer choices that were built on a foundation of valuing and including.

Including as a Care-ful Journey

Diane and Chad's journey is a clear reminder that images, meanings and choices surrounding disability are not constructed in isolation; rather, they are situated in a network that also affords image and meaning and, therefore, often controls choice. Their journey also demonstrates that parental coping variables, such as locus of control and agency, may not be sufficient to counter attitudes of society toward persons with disability. According to the research and parent literature, life management is dynamic and can be affected by transition points. Therefore, when children and families move through typical developmental stages, changes can occur in image, meaning and choice, affected both from within the family system and through involvement with the wider social system, which can have a significant effect on a family. For this reason, linear models of family coping should be balanced by more dynamic models of a cyclical nature as proposed in this paper.

In addition, it is important to examine further the statement that this is a non-inclusive world (i.e., that society is non-inclusive toward individuals with disabilities and special needs). This topic will be explored using data from the interviewed parent, from literature cited above, and by examining events unfolding in Alberta (home of the second author), even as the paper is being written.

Green (2007) urged awareness of the socio-cultural constraints experienced by families, underlying cause of much of family and parental distress. Green et al. (2005) attributed social isolation and status loss for these families to reactions of others to their situation, to negative social constructions of disability (a devaluation of the child with disabilities), defining society's perceptions and treatment of those with disabilities. Families struggle within a cultural context, which offers little in acknowledgement of or response to their needs. Gottleib (2002) called for "responsive communities" with support for those with disabilities and their families, woven into the moral and ethical framework of the society, a commitment that would require massive and likely unrealistic alteration of social priorities.

Diane, the parent in the case study, felt the societal reaction to her child with a disability hours after the child was born, when both the doctor and social worker urged her to abandon her disabled child. Even within the school system, where there is the expectation of an inclusive environment for young people with disabilities, this parent found that she had to fight for inclusion as opposed to isolation of her child, particularly in the junior high and high school years. Particularly in high school, Diane found teachers to be unsupportive and unable or unwilling to do program modifications, to provide an inclusive learning environment for her son. Compellingly, she fears an adult world that segregates persons with disabilities; fears service cutbacks, stereotypes, segregation and loss of value, health and energy, for her and her son.

At time of writing, the second author has been attuned to media issues and concerns, related to persons with disabilities. In a political climate of uncertainty, recession and government cutbacks, a couple of media examples will serve to illustrate the tenuous hold on including persons with disabilities within the larger society. Jeff Lee (2010), writer for the Vancouver Sun, discussed the separation of the Canada-hosted Winter Olympics this past February, followed two weeks later by the Canada-hosted Paralympics. Lee quoted Sir Phil Craven, president of the International Paralympic Committee, as perceiving the Paralympic games as a way of changing people's perceptions of achievements of others who have overcome physical and emotional challenges. The Paralympics are about "extraordinary athletes who are exceptionally talented in their chosen sport," a movement "about changing perceptions, dispelling myths and challenging assumptions" (Carla Qualtrough, president of the Canadian Paralympic Committee, as quoted by Lee, 2010, p. C1). Yet, while these bold words were spoken, only local (British Columbia) live TV coverage was instated after some public outcry about the intention to broadcast only delayed, recorded coverage of Paralympic events. Dr. Bob Steadward, founder of the International Paralympic Committee (IPC), argued for serious discussion (MacKinnon, 2010) of integrating the Winter Olympics and Paralympics. The current IPC president, Sir Phil Craven, has dismissed the notion of such an integrated Winter Games. Steadward is quoted by MacKinnon

as saying about such integration, "It's not that the task is impossible, but once you stop pushing the rock, look out because it's going to roll right back over top of you… maybe, in 20 years or more we won't even have this kind of a conversation… maybe no one will differentiate between Olympic and Paralympic sport. In the end, it's all just sport" (p. C7).

On March 23, 2010, the *Edmonton Journal* carried an article by Paula Simons, which should instill fear of loss of support in the hearts of parents and foster parents of children with severe disabilities. A week prior, the Alberta Provincial Minister of Children and Youth Services denied, in the Provincial Legislature, that there would be cuts in compensation to foster parents of severely ill children (estimated as only about 20 to 40 children in the Edmonton area). Next day, such cuts were announced to foster parents of children with the most acute medical needs. The cuts were denounced the following Monday by a member of the Provincial Opposition as "awe-inspiringly cold-hearted" (p. B1) and were immediately rescinded by the Minister, with an apology to the affected foster parents. Such cuts would hardly have been a significant cost-saving measure, and serve only to instill greater fear of inadequate support in the hearts of those parents and foster parents, in whose hands lie the care and well-being of our most dependent and vulnerable children.

While such societal threats of possible cuts and other negative changes exist on the horizon, we are losing sight of a care-ful society, and becoming a society which determines worth on the basis of financial value of the individual. At the same time, "watchdog" agencies, which speak out in protection of those who cannot speak for themselves, are also being faced with cutbacks, or closure (Sinnema, 2010). Who, then, will speak out for those with disabilities? The parents cannot do so alone, in face of a non-inclusive, non-caring society.

Times of fiscal restraint are, indeed, difficult. But they also offer an opportunity--to reassess priorities, to discover what is really important and valuable in life, and to determine the basic values upon which society will be structured. Green et al. (2005) remind us that though disability is experienced by an individual, stigma and segregation are

relational constructs that exist in the space between people—in the images and meanings afforded to people and the choices made therein. Care also exists in the space between people and signifies including and belonging. The challenge for society, then, is to determine whether and how to engage in care-ful image-making, meaning-making and choice-making with regard to all of its members. It might well be that our response to those with disability is an indicator of the kind of people we have chosen to be, and a significant determinant of who we are becoming.

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