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Four types of integration in disability identity development

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Abstract

Integration is a recurrent theme in classic theories of personality development, reflecting the perennial human struggle to resolve opposing pulls toward separation and unity. Identity development is examined in this paper as a particular case of the striving for integration on both individual and group levels. In the context of minority identity development, the steps toward achieving a sound disabiltiy identity are discussed with respect to intrapsychic, interpersonal, and social dynamics. Four types of integration underlying disability identity development are delineated with examples: (1) 'coming to feel we belong' (integrating into society); (2) 'coming home' (integrating with the disability community); (3) 'coming together' (internally integrating our sameness and differentness); and (4) 'coming out' (integrating how we feel with how we present ourselves). The paper ends with a discussion of the significance of this integration process for personal empowerment and disability rights activism.

Keywords: Disability; Identity; Integration; Minority; Personality development; Empowerment

1. Introduction

Integration, defined as the act of incorporating or combining into a whole, is a perennial theme in human development. It appears in some form in most classic theories of personality development and is associated with positive outcomes, such as maturity, psychic comfort and emotional health. As a clinical developmental psychologist, I have always been captivated by the familiar plot of personality integration: the child or adult is plagued by psychological disorganization due to maturational changes or life crises; with support and time for exploration, the individual begins to make sense of jumbled feelings and perceptions; finally, disparate elements of the personality synthesize into a new, stronger, more differentiated level of personality organization allowing for im-

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proved relationships with the social environment. In developmental psychology, integration rules!

Much of the dramatic tension in this plot is sustained by the lively polarity of separation and unity that is crucial to integration across theories. Sometimes the drama takes place entirely within the individual, calling for unification of distinct areas or functions of the psyche. In psychoanalytic theory, for example, the healthy psyche must harmonize three potentially conflicting parts of itself: the moral taskmaster (superego), the hedonistic impulse network (id), and the realistic self (ego). Other times, the spotlight is on the relationship between the individual and the social environment. Rogers (1951), for example, emphasized the importance of congruence between our view of self and the totality of our experience in mediating self-esteem and psychological health. He spoke about the desirability of congruence between our internal self-image and our ideal self or the way we wish to appear to the world. In both cases — (1) integration within the individual, and (2) integration of the individual with respect to society — any failure to achieve integration implies the risk of wastefully expended psychic energy and the pain of inner turmoil. It also signals an unfortunate arrest in the individual's journey toward advanced psychological functioning.

2. Identity development

An important case of the human quest for integration is identity development. Again, the dynamic tension between separation and unification is highlighted. Based on her observation of infants, Mahler (1968) theorized that humans are born lacking a sense of distinctness from surrounding objects, including human caregivers. According to Mahler, newborns experience external and internal stimuli in a confused matrix of sensations, unable to sort out their own actions and feelings from those of others. Through interaction with the environment and the nurturing parent over time, the infant learns where she or he ends and others begin — a process Mahler referred to as separation-individuation. A primitive identity forms when the infant can unify his or her own experience into a continuous sense of self separable from the existence and actions of others. Psychological integration in this theory requires a declaration of independence from the parent.

Mahler's critics have questioned her emphasis on personal autonomy as the goal of self development. Stern (1985) attributed less confusion and more perceptual awareness to infants as they process interactions with the parent and the environment. He agreed with Mahler that interpersonal experiences teach the infant a sense of 'self vs. other'. He emphasized, however, not the goal of separation from nurturers, but the importance of developing the self in relation to others. He did not view the child's bond to the parent as primitive and inferior to a state of independence from the parent. Rather he viewed that bond as a valuable prototype for learning how to form relationships. Whereas Mahler may have seen the 'mother's' task as trying not to interfere with the infant's growing independence, Stern viewed the caregiver as an integral player in helping the infant fashion a sense of 'self with other'. His theory moves the process of integration from the exclusively inner world of the individual to the interactive space between the individual and others.

Erikson (1968) stands out among personality theorists for his focus on identity development as an essential life task. Although autonomy is an important goal of early (toddler) development in Erikson's theory of human development, he placed the central task of identity development in the period of adolescence. Separation once again is a key goal, as adolescents question and distance themselves from the expectations, values and identities handed down to them from their parents. In this case, such separation allows individuals an opportunity to think through and try on roles and values until they are prepared to integrate all of their preferred options into a new signature identity. While the emphasis is on the individual's unique construction of self, Erikson described identity achievement as a prerequisite to the formation of genuinely intimate relationships in adulthood. Again, the task of defining a distinct or separate identity results in both greater

inner wholeness and in an enhanced ability to unite with others in relationships.

3. A tale of group identity

Theoretical discussions of self-delineation and its importance for psychological intactness and interpersonal competence occurred throughout my clinical training. I fondly remember a clinical internship supervisor who was a devotee of Mahler. In class, he spent hours on 'separation-individuation' and the development of the autonomous self. He was a kind, fatherly mentor who invited our internship group to his home for dinner to celebrate our own impending transition in identity from students to independent professionals. Predictably, given the circumstances, after-dinner conversation became a game of congenial competition as we vied to impress him with our experience and insight.

The conversation progressed from work-related issues through the arts and settled on politics. When the group took up the controversial issue of our government's responsibilities to undocumented immigrants, our host presented a position that stunned me. He asserted that all people who come to the United States from other countries should strive to assimilate into our culture. Specifically, he expected them to check their languages and 'foreign' customs at the American shoreline and to blend into the mainstream as quickly as possible.

The statement immediately struck me as utter hypocrisy. As my teacher, he had been successful in convincing me of the importance of separation-individuation for persons. Why did he disparage the preservation of distinct identity by a group? If individuals gained strength by claiming their own identity, how could we deny that right to distinct communities within our great cultural melting pot? Years later, I realized my response had been more than an impulsive defense of the rights of the underdog. I reacted, albeit unconsciously, as a member of a minority community of my own, namely people with disabilities. Although I had made no conscious identification with a 'disability community', I was leaping from my understanding of individual identity to an interest in group identity in a single bound.

Shortly following that significant dinner, I learned about the independent living movement and the disability rights struggle. Particularly interesting was the emphasis on integrating people with disabilities into society. I wondered how people with disabilities would optimally manage the twin pulls of separation and unity in striving for integration.

In the past 20 years, I have listened to persons with disabilities and their allies talk about their pursuit of integration, both within themselves as individuals and socially as minority people navigating the cultural mainstream. These have been 20 years of active identity formation. Inspired by the civil rights struggle and the pride movements of other minority communities, we who have disabilities have worked to define who we are and our place in society. Perhaps more than any other minority group, however, disabled people's identity strivings have been impeded by the nagging details of our oppression. Inaccessible environments and transportation systems are barriers to community organizing. Poverty keeps resources beyond reach. Categorization by medicine and social service systems perpetuates our separation from each other. Social values that deem disability a fate worse than death discourage us from identifying as disabled individuals or seeking the company of stigmatized peers. Nonetheless, the drive for wholeness and definition has resulted not only in organizations and public policies safeguarding our rights as citizens but also cultural efforts to celebrate our differences as valuable.

As other marginalized communities have struggled to do, we with disabilities are trying to resolve central dilemmas in the formation of individual and group minority identity. How much do we wish to assimilate into a dominant 'parent' culture that judges our differences as defects? Can we claim citizenship and all the resources of the mainstream without losing the benefits of minority unity? Is it prudent to call attention to our differentness in a society that may use deviance as a basis for discrimination? Is separating from the mainstream to build a disability community simply a capitulation to the forces of exclusion?

These are all questions about the potential risks and rewards of a growth process that involves at least temporary relinquishment of former attachments, redefinition of self, and reconfiguration of relationships to others and society. They are questions about the inherent tensions of separation-individuation in the service of improved integration as a foundation for identity.

It is remarkable how many times the theme of integration emerges in the discourse of people with disabilities. As a psychotherapist, I heard a yearning for wholeness and belonging that surfaced repeatedly in the complaints of persons with varying disabilities and backgrounds. The theme is expressed with poignancy in the writings of disabled students, activists and artists. More recently, I detect such longings in the messages people with disabilities send through the Internet.

I discern four types of integration addressed in disabled persons' discussions of who they are and where they belong. The following section lists them and describes their salient features.

4. Four types of integration

4.1. Coming to feel we belong (integrating into society)

Both those who grow up with disabilities and those who must make sense of disabilities acquired later in life are ultimately faced with the same task: they must work out comfortable identities and social roles despite their membership in a socially marginalized group. Often the first move toward positive identity for disabled persons in the United States is the assertion of a right to inclusion in society. Such assertions take many forms and reflect varying degrees of conviction. Children with disabilities often express the desire to attend neighborhood schools 'with everyone else'. Adults talk about equal opportunities for employment. With anti-discrimination law backing them, it is now commonplace for people with disabilities to expect and pursue access to buildings, transport, recreation, health and reproductive services, the arts, social relationships, etc. One of my favorite disability rights t-shirts summed it up in the mid-1980s. It simply said, 'I Want It All!'

Yet it is only recently that most people with disabilities have felt deserving of such claims. As objects of charity or targets of professional remediation, we with disabilities have been historically trained to view ourselves as properly excluded from 'normal' life. It took some particularly hardy souls among us to resist our programming sufficiently to initiate the disability rights movement. Instead of hoping for a cure to restore our social value, we could assert our rights to the mainstream in spite of our impairments. More recently, as exemplified by the Americans with Disabilities Act, we have asserted the right to be considered equal in value to anyone else, not in spite of, but with our disabilities. We have dared to expect accomodation for our differentness. We have also dared to place the blame for 'not fitting in' more on the creators of restrictive environments, roles and occupations, and less on ourselves.

4.2. Coming home (integrating with the disability community)

Although some people with disabilities feel comfortable associating with disabled peers, others vigorously avoid such contact, especially in activities or gatherings primarily for 'the disabled'. My discussions with disabled friends, clients, and research participants reveal several explanations for such avoidance, including:

- Contact with other disabled persons evokes disturbing memories of special schools, custodial institutions and other sites of disability segregation.
- Participating in disability-specific gatherings seems like acquiescing to society's unwillingness to provide access to the mainstream.
- Some of us have internalized the public's fear and devaluation of disability and, therefore, reject people with disabilities as valuable companions.
- Some who, in fact, enjoy the company of disabled peers avoid it due to fears of stigma contagion, i.e. If I affiliate with 'my own kind', I'll be viewed by others, not as an individual, but in terms of group stereotypes that say the disabled are weak, incompetent and pitiful.

For some people with disabilities the issue of peer contact is moot. Due to isolation caused by transportation and environmental barriers, inadequate personal assistance for mobility, or living in sparsely populated areas, they have few options for meeting others with disabilities.

Despite these considerable attitude and access obstacles, however, people with disabilities often find each other. They may meet while seeking disability-related services or information. They may turn to peer groups for strategies in living or emotional support, or they may find themselves shoulder to shoulder in a disability rights action. Once contact is made, many persons with disabilities unexpectedly find they enjoy the company of others 'who have been there'. While continuing to value their relationships with non-disabled friends and family, they recognized a level of connection unique to their relationships in the disability community. They describe this connection in various ways. Some mention 'acceptance'. Others emphasize the ease they feel in talking with others who understand them without the need to stop and explain experiences and terms related to living as a disabled person. Many have started to articulate a sense of disability 'community', 'culture', or even 'family'. However, the description of the experience that I find most interesting and that I hear often these days — especially from individuals who discover the pleasures of such companionship after years without it — is the simple and poignant phrase, 'coming home'.

4.3. Coming together (internally integrating our sameness and differentness)

In over a decade of clinical work with adolescents and adults with disabilities, I watched clients struggle with a surprisingly common barrier to psychological wholeness. It originated not at all in the disability, itself, but in the manner in which family members, professionals and other significant social figures framed the impact of disability for the disabled individual. They conveyed to the individual that she or he should seek value in parts of his/her being that had not been impaired by the disability. For example, a person with paralysis should be thankful for a working brain; a blind person still had hearing; a person with a learning disability was lucky not to be 'crippled'; a hemiplegic had one unaffected side. These unaffected parts would usually be referred to as 'still good', implying that the disabled parts were bad and should be forgotten.

The larger implication, of course, is that the individual with a disability can never be wholly acceptable. The mandate accompanying this reality is that such persons must try as hard as they can to overcome their defective, invalid parts. They must dazzle others with their worth in hope that the pluses and minuses will wash and the final summation of their assets might approach the gold standard, namely 'normality'. In this framework, there are two choices. One either chooses the course of exhaustion by ceaselessly laboring to measure up to an ill-fitting standard, or one 'gives up' and surrenders to invalidity. In either case, a sound identity is impossible because integration is impossible. The self is split into 'good' and 'bad'. However diligently the individual works at self-development, there will be gaps in identity because parts of the self are disowned.

The learned rejection of the disabled self can leave the individual in a painful state of disintegration. A graduate student with a learning disability described her torment in an autobiographical account:

> Because of society's expectations, the soul of the disabled individual is constantly engaged in a struggle in which it tries to resolve two opposing sides of the conflict. Half of the soul promotes the struggle to be proud and accepting of who and what that person is. The other half argues that this person is less and inferior, no matter what they do. As a result, disabled individuals often become divided against themselves...This schism has been something that has been very fundamental to the formation of my own identity (Reiling, 1993).

The attempt to fashion an identity that excludes important parts of the self, i.e. the disabled parts, then, results in a sense of self in conflict or a self-image riddled with significant gaps. In either case, the resulting identity is not sufficiently sound to support stable, resilient self-esteem. Without stable self-esteem, it is difficult for the individual to sustain her/his sense of worth and

entitlement to a place in society. A disintegrated identity, then, can undermine the stability of other types of integration, including one's pursuit of integration into the mainstream and one's comfort in associating with disabled peers.

In the last 10 years, Americans with disabilities have begun to advance in self-validation from an insistence on equal rights to a declaration of pride (Longmore, 1995). As discussed above, through the disability rights and independent living movements, people with disabilities had progressed from asserting their entitlement to equal treatment in spite of disabilities to affirming their worth with their disabilities — no apologies for being different. Now they have begun to proclaim their distinct value because of disabilities, claiming the potential of disability to bring unique perspectives and enriching experiences into their lives. They are celebrating a disability culture including a history, language, art, customs, humor and worldviews characterizing the community of people with disabilities and challenging the values of the non-disabled world. This important advancement in group identity has fostered historic developments, such as the founding of the Disabled Student Cultural Center at the University of Minnesota and the Institute on Disability Culture in Las Cruces, New Mexico. It has also spawned numerous conference presentations, research projects, arts events and committees in academic/professional organizations examining the positive aspects of disability identity and culture. In autobiographical work, disabled artists are exploring and integrating their disabilities into their art and representations of self, as in Cheryl Marie Wade's poem, 'Gimp Hands':

> Mine are the hands of your bad dreams
> Booga Booga from behind the black curtain
> Claw hands
> The Ivory girl's hands after a decade of roughing it
> crinkled puckered
> sweaty and scarred
> A young woman's dwarfed knobby hands
> that ache for moonlight
> that tremble
> and struggle
> Hands that make your eyes tear
> My hands
> *My hands*
> My hands that grace
> your brow your thigh My hands
> in your hands (Wade, 1991)

In order to affirm the disability experience as a positive and important feature of our identities, people with disabilities have had to separate and individuate from a parent culture that fears and devalues disability. To reclaim our disabled parts and become emotionally whole, we have had to reject the values that reject our differentness. This has been a complicated endeavor because like gay and lesbian persons, our families of origin are predominantly from the majority culture. Because our links to the dominant culture are so deep, however, they motivate us to cultivate our relationship skills and to define our 'selves-in-relation' to the parent non-disabled world. Many of us have been asserting our right to maintain simultaneous links to both our parent culture and the disability culture — in other words, our right to embrace our sameness as part of the human family as well as our differences as part of the disability family. Our growing comfort with multicultural ties holds the promise of healing conflicts within us as well as smoothing rifts of misunderstanding between us and people lacking disabilities. The student quoted earlier explains how her involvement with the disability community helped her resolve the 'war' inside her and allowed her to integrate her disability into a positive self-image. This resulted, moreover, in better relationships with the non-disabled world:

> I... began to look at my disability in a very different way. This change was catalyzed by experiences I started to have with other disabled students. We began to 'hang out' and I enjoyed their company, even though they were peers with whom I was initially very reluctant to be associated. I had finally found a group of people with whom I did not have to consistently play the role of the 'happy overcomer'. I no longer regard disability as an inherently negative condition, but rather as one of the unique and positive characteristics that comprise our society as a whole. I can honestly say that I like myself, not despite, but because of my differences. And as I have come to value my disability as an integral part of who I am, others have too. For once, I began to let people pass through the carefully guarded gate of the wall which I built to separate me from others. After having reached the point of accepting and respecting myself and my differences, it has been much easier for me to form a positive relationship with society (Reiling, 1993).

4.4. Coming out (integrating how we feel with how we present ourselves)

Integration between our private knowledge of self and the ideal image we wish to present to others is one of the final thresholds to positive disability identity. To feel sufficiently comfortable to 'be oneself' unwaveringly, regardless of circumstances, is a late-stage identity accomplishment for anyone. It is a particularly significant accomplishment for members of socially oppressed and marginalized minority groups. Researchers who have studied the path to positive individual and group identity for African–Americans, gay men and lesbians, and other ethnic/cultural minorities, have been mapping out categories or stages of minority identity development. Although the stages may differ by name, number and description depending on the line of research, the trajectory generally starts with the minority individual's desire to assimilate to the dominant culture, passes through a period of conflict and separation, and ends with the individual finding personal integrity, a proud identification with the group, and a readiness to construct improved relationships in the mainstream. This outcome offers minority members a new freedom to be themselves without internal conflict or social discomfort. It allows the real self and ideal self to reach congruence. With nothing to hide, the individual can 'come out' to society as gay, Asian, Jewish, etc.

Disabilities come in many degrees of visibility. Although it may seem that only those with hidden disabilities can play the game of 'passing', all people with disabilities are socially pressured to cover their differences and emphasize their normality. Some work through life to prove their validity at the cost of burn-out, fear of failure, and, ultimately, the lack of a comfortable identity. At almost every disability conference I attend, I still meet 'successful' persons with disabilities who are recognized and awarded by society for their achievements but who are privately tired and alienated. They dare not be themselves in public because they do not yet fully accept their differences and others who are different. They cannot be counted on to critique the values of the dominant culture, so busy are they with meeting the standards.

Also at those conferences, there is usually a familiar commotion in the hallways caused by people with disabilities spontaneously stopping to exchange news, ideas and laughter. These connections radiate energy. The parties may show some wear from years of advocacy battles but no strain from wars within. Such persons have forsaken 'normality' in quiet, healthy defiance. In disability groups and in greater society, they function with a certain down-to-earth grace. They are persons who identify without hesitation as disabled, who have 'come out' to all the world as no more or less than who they are. Allowing themselves to be disabled frees them to explore more fully their authentic selves and to reach out to others, disabled and non-disabled. As one person expressed it in an Internet post.

> I have always remained apart from the disabled community until now, feeling that I did not belong to either the disabled or non-disabled camp because I can walk in a fashion with crutches and have been able to get a job. However, I have become very interested in how disability and the way society reacts has affected me and the way I think. I now want to try and get involved in this field and see if I can contribute my own thoughts after 30 years in the 'wilderness' alone. Being part of [a disability network] is the first step to finding a place where I fit and can contribute to. I am not ashamed of my disability and it is time I came 'out' and explored more what it means to be me.

5. The right to integrate

The 'coming out' process is often the last step toward disability identity in a path that begins with a desire to find a place in society, continues with a discovery of one's place in a community of peers, and builds to an appreciation and acceptance of one's whole self complete with disability. Viewed another way, these steps travel a liberating arc away from society and back, moving from a desire for social integration, through a distancing from mainstream society to focus on both group affiliation and personal integration, to a renewed effort to relate to society from a position of greater self-definition.

We are beginning to oppose the sources of our disintegration as staunchly as we have fought environmental barriers and job discrimination. The emerging disability pride and culture movements may vanquish the most defeating and insidious form of oppression we have endured. Taught to disown our disabled parts and to avoid our disabled sisters and brothers, we have been profoundly handicapped in securing our rightful place in society. After all, we have been split into good and bad selves, split from each other, and split from greater society literally through environmental impediments and symbolically through feelings of invalidity. If the identity theorists are correct, the splitting must be healed through integration if we are to grow and prevail. Each of the four types of integration underlylng disability identity reinforces the others and brings us closer to our human potential. Together they lead us to our whole selves and to a position of unprecedented personal and collective strength.

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