

Minority Survival Skills: Facing Internal and External Ableism*

One of the most common complaints of the chronically ill, those in chronic pain and/or the disabled is coping with ongoing ableism. Ableism is a set of prejudicial beliefs, attitudes, policies and/or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities; and often rests on the assumption that disabled people need to be 'fixed' in one form or the other. Ableism holds that able-bodied statuses are superior to disabled statuses.

People can experience ableism from friends, the media, family, work, community and (to many people's shock and disappointment) within the healthcare community itself. Reinforcement of ableist beliefs, attitudes and actions can be so strong that someone with a disability can develop prejudicial and discriminatory approaches to themselves that reinforce shame, a poor self-concept, self-esteem issues, and in some cases, even self-loathing. We call this, "internalized ableism."

Within this document, you will find a list that names and discusses two polarized identities the disabled (including other minorities or stigmatized groups) can adopt in response to their disability and ableism itself. Identities are the qualities, characteristics, beliefs and thought and behavioral patterns we adopt that help us define who we are as people. One identity is associated with more distress, a lack of problem resolution and general and ongoing feelings of: alienation, invalidation, isolation, disempowerment and victimization ("Self-Rejection: The Victim Identity"). The other approach is associated with improved mental and emotional health, connection, protection, validation, improved self-esteem and self-concept, empowerment and increased positive adaptation to disability ("Self-Acceptance and Celebration: The Empowered Identity").

<p style="text-align: center;"><u>Self-rejection: The Victim Identity</u></p> <p style="text-align: center;"><i>(Disempowered: helplessness, hopelessness; “shrinks” sense of self to cope with stressors and conflicts - sees power, relief, protection and possibility as only residing outside of the self)</i></p>	<p style="text-align: center;"><u>Self-acceptance and Celebration: The Empowered Identity</u></p> <p style="text-align: center;"><i>(Empowered: hopeful, powerful, enlarges sense of self and actions to meet stressors and conflict - sees power, relief, protection and possibility residing within the self)</i></p>
<ul style="list-style-type: none"> • Engages in self-blame: sees self as “the problem” or the whole “problem,” and takes full responsibility for “fixing” the situation. As humans we seek a sense of power yet simultaneously face many things we don’t have power over, or complete control over (e.g., our bodies, other people, etc.). Often, we unhelpfully cope with this through self-blame as it initially gives a distorted sense of power because it’s directed towards the self, yet it is ultimately misleading as it does not account for others’ roles, context and situations, and/or “the whole package;” self-blame also includes an amount of moralizing and judgment which tends to decrease mental health; • Accepts others’ judgments and beliefs (and those of other minorities) without critical reflection and challenging them within and without, when appropriate; • Try to “fit in”/“pass” as a defense: denies, rejects, suppresses or sacrifices aspects of whole self (including disability) to achieve counterfeit closeness; pretends to not be disabled; Isolates from others; hide symptoms, lies and avoids, creating a sense of “wrongness” and alienation while in the midst of others; 	<ul style="list-style-type: none"> • Looks to see and validate the whole situation, what is: my role, your role, society’s role, nature (if atheist or agnostic)/the universe’s/God’s role (if religious or spiritual), the illness’ role, medical providers’ role, etc.? Create a comprehensive view of the situation and synthesize all of the evidence and observations together to make a holistic perception that is closest to the truth; • Question authority when appropriate and assert self when faced with prejudice, dismissal, violation of rights, invalidation, etc.; • Externalizes the problem as appropriate. For example, “Just because the doctor was unable to find anything in terms of causes of my illness, it means he or she is limited NOT that I do not have symptoms that are worth kindness, attention, curiosity and respect;” • Knows ethical and legal rights and asserts them when appropriate; • Engages in fair comparisons: compares self to others with same diagnoses (not to the healthy), or better yet questions the utility of comparisons in general;

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<ul style="list-style-type: none"> • Obsesses, worries and ruminates: unhelpfully repeating images of past struggles and grievances, and projections of the future in mind for a counterfeit sense of readiness and control; fixates on the uncontrollable; • Solely bases actions on expectations of what others want, or on perceptions of what others want; • Automatically believes painful thoughts without critical reflection and/or exploring other perspectives; • Refrains from making adaptations to new limitations; • Focuses on changing others to be valid/ “okay;” • Minimizes own strengths, accomplishments and successes; 	<ul style="list-style-type: none"> • Acknowledges wounds from facing ableism, validates pain and integrates self-compassion into identity and perspectives (engages self (and others) with: gentleness, kindness, interest, recognition of one’s connection to others because they are going through similar/the same thing(s), etc.) • Identifies faulty reasoning that increases sense of alienation, isolation and marginalization and challenges it both psychologically and behaviorally; • Recognizes accomplishments as someone who is resilient, facing something that was once unimaginable to them; • Seeks reliable information about illness, pain and disability identity and integrates accurate information into thoughts and self-concept; • Identifies, sets and maintains healthy boundaries for self-preservation and protection; grants autonomy to self and others when confronted with others unwilling to listen, change, grow, etc.

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	<ul style="list-style-type: none"> • Connects to other minorities (e.g., people with same diagnoses, disabilities, etc.); • Uses own self-understanding and acquires knowledge to define what is right for the self; Sees life, others, health & illness, this world and self as complex; greets complexity with compassion, patience, openness, curiosity, self-kindness, self-respect, etc.; • Accepts limitations and adapts to them; adapts to continue hobbies and interests if possible; if not possible, reinvests in new hobbies, interests, relationships, etc. that accept disability; • Recognizes when slipping into shame and confronts it (internally and externally); • Recognizes that from one perspective because we are individuals none of us ever completely “fit in;” sees that one is not alone in feeling alone at times;

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	<ul style="list-style-type: none"> • Grieves and mourns losses while balancing process with recognizing gains and growth (e.g., “My illness might not change, but I can see that my emotional openness and strength is growing”); Celebrates successes and congratulates self; • Embraces ambiguity as inherent to life and the human condition (no one fully “escapes” the unknown; releases self from having to “know,” and “figure everything out;” re-focuses on area of power and cultivates respect and appreciation for mystery.

Those who are disabled can tend to self-blame when those in family and society don’t understand (or care to understand) the lived experiences of the chronically ill and disabled. Some may also blame the disease for all of their problems. Undoubtedly illness causes challenges and the reality is that according to the Center for Disease Control (in the U.S.A.) 60% of the population is managing at least 1 health problem. This, by definition, makes illness and experiencing health problems what we call, “normal.” Due to this, some critically reflect, “If this is true, is the bigger problem that I’m ill or disabled or that society doesn’t structure: beliefs, attitudes, policies, work, laws, rules, education, spaces, etc. to include disability?” This is called the, “Social Constructionist Model of Disability.” The Social Constructionist Model of Disability is also a perspective that recognizes there is not one universal experience of disability; disabled people have different experiences across time and cultures, and ideas about what disability means and who is disabled are defined by humans. Some people find it more accurate, helpful and liberating to adopt this model as their perspective on illness and disability.