Clinical Focus

Leveling Up Regulatory Support Through Community Collaboration

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Purpose: No group has more stake in the game than the community that researchers, educators, and practitioners aim to serve. In our field, we must recognize not only that autistic people are those most affected by decisions around programming and policies, but that they are key informants in decisions around the conceptualization, implementation, and evaluation of educational programming for autistic learners. Too often, they are left out of these discussions altogether. To illustrate the process of community collaboration, we discuss emotional and energy regulation (ER), a top priority among autistic people based upon their viewpoints.
Method: In this clinical focus article, we outline what emotional regulation is, why it is relevant and often challenging for the autistic population, the shortcomings of current practice, as well as practical strategies and ways of thinking about supporting ER for autistic learners. We provide theoretical insights as well as firsthand accounts from a diverse group of autistic people. Each autistic person contributing their perspective in this clinical focus article provided written consent for their participation, as well as direction as to how they wanted to be cited and acknowledged. Quotes were gathered from personal communications, social media posts, and online sources. The clinical viewpoint and materials and tools presented throughout the clinical focus article are the works of the authors that have been informed by the autistic community.
Results: Based upon the qualitative data presented in this clinical focus article, incorporating the autistic community voice when devising tools and strategies is validating of their experiences and generates useful supports.
Conclusions: Using a framework similar to the one presented here for engaging the autistic community will help to facilitate the conceptualization of more reliable, valid, and effective supports, goal-setting, and programming overall. Future directions related to the value of empirical study of the tools and strategies developed through such a process are offered.

The ultimate goal of research is to improve the quality of life and well-being of populations. However, the research pipeline often takes years to impact clinical or educational practice and, in many cases, does little to address the real needs of vulnerable populations (National Institutes of Health [NIH], 2011). As such, community engagement must become a central focus of professionals working in the field of autism. In order to level up the scope and ability of traditional educational practice to support autistic individuals in authentic and meaningful ways, it is imperative to listen to the autistic community. Their firsthand experiences in education, both positive and negative, should be the cornerstone of how we design, implement, evaluate, and subsequently improve educational programming for autistic students. This involves forming true, trusting partnerships that incorporate ongoing collaboration between researchers, educators, therapists, and members of the community they aim to serve (Joosten et al., 2015). It also means understanding that the community members, in this case autistic people, are the primary stakeholders and, thus, key informants in designing, implementing, and assessing educational practices in terms of the outcomes that are meaningful for them.

A primary goal of true collaboration between research, practice, and the community is to determine the needs of the community from their perspective. If we act or design before

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Editor-in-Chief: Brenda L. Beverly
Editor: Laura B. Green
Received August 14, 2020
Revision received November 10, 2020
Accepted November 25, 2020
https://doi.org/10.1044/2020_PERSP-20-00197
Publisher Note: This article is part of the Forum: Communication Choice and Agency: Thinking Beyond Spoken Language for Individuals on the Autism Spectrum.

Disclosures
Financial: Amy C. Laurent and Jacquelyn Fede do, at times, receive honoraria when they are asked to present these materials at professional conferences. Jacquelyn Fede is supported by Institutional Development Award Number U54GM115677 from the National Institute of General Medical Sciences of the National Institutes of Health, which funds Advance Clinical and Translational Research (Advance-CTR). No direct financial support was received for this work.
Nonfinancial: Amy C. Laurent and Jacquelyn Fede acknowledge that they are the Co-Directors of Autism Level UP, LLC. The therapeutic tools presented in this clinical focus article are the property of Autism Level UP! These materials are freely accessible online. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

we are clear on this, we are sure to fail in being able to provide support. When asked directly about daily challenges and priorities for support, autistic individuals frequently highlight emotional or energy regulation as an area of challenge that impacts quality of life on a daily basis.

> *Jacquelyn—Experiencing stress is overwhelming…in the worst of ways. It's like—it cannot be contained; it has to come out. And not in words. In fact, I don't really think or experience words when I am stressed. It's a very physical experience. In the midst of it - in a moment where I am highly stressed—you know, I pace, I grab my head and I scratch my scalp, I bite my cuticles and my hands um more and deeper and harder than usual. It feels like I am in this chaotic mayhem, and like I need to throw myself full force into a wall or smash things. And in my most stressed times, I—I do that.* (Laurent et al., 2019, 08:58)
> *Tee Monet—I still whimper at times as an adult. To me it doesn't signal immaturity, but desperation. I'm hungry and there are too many choices. I know if I'm hungry much longer I may melt down and since I'm already anxious I'm having trouble forming words. I am anxious so I'm having trouble processing my thoughts. I am crying because I don't know how to get you to understand all of this at once. I am feeling so many things at once.* (Tee Monet, personal communication, June 12, 2020)
> *Michael John—I do believe firmly that from our end, that 90% of our problems as adults in life are caused by an inability to manage our challenges for emotional regulation.* (Laurent et al., 2019, 15:25)

These types of insights help therapists and educators see the real need for a major shift in educational programming. They highlight the need for comprehensive changes and overhaul, from goals and aims to design, procedures, tracking, evaluation, and training. Historically, educational efforts have focused on remediating and extinguishing problematic behaviors (i.e., dangerous, destructive, disruptive behaviors) that tend to arise from emotional regulatory difficulties. However, behaviors that have been deemed problematic have also tended to include things that simply look different or are unexpected to neurotypical people (e.g., flapping, vocalizing, rocking, pacing, echolalia, lack of eye contact). In both cases, to address these behaviors, educators and therapists often turn to traditional behavior management approaches that are grounded in behavioral learning principles. Autistic individuals are clear that the interventions to which they are subjected often focus on external, resulting behaviors rather than their own, valid underlying experiences and that this is harmful and dysregulating, rather than supportive, useful, and affirming.

> *Patti—discussing compliance-based therapies focused on extinguishing behavior—Two results emerge: One—anxiety increases, and Two—there is internal damage due to our communication not being honored and strong emotions like rage, SIBs, room destruction, and suicidality.* (Laurent et al., 2019, 12:52)
> *Autistic Typing—They believe that Autism is a willful "behavior" not a disability requiring support. They use superficial methods of manipulating outward behavior without any regard for the specific support needs that a child needs in order to learn and apply their knowledge across multiple contexts. ABA reduces a child's disability to outward behavior with no concern or regard for understanding or long-term consequences.* (Autistic Typing, July 25, 2020).
> *Stephen—Another area that is important to address is behavior plans; token economy; focus on compliance-driven programs and how they can be potentially dangerous and damaging and, in some cases, creating post-traumatic stress syndrome to autistic individuals.* (Laurent et al., 2019, 12:35)
> *Jacquelyn—To control those emotional experiences and how they look is to control me and who I am. It doesn't just feel "yucky" or tiring or boring. It isn't just unpleasant—it feels like living hell. Like total confusion and a feeling of being lost or incompetent.* (Laurent et al., 2019, 11:26)

These first-person accounts give credence to and substantiate emerging research findings. For example, Kupferstein (2018) found through a survey administered to 460 autistic adults that autistic individuals who had been exposed to applied behavioral analysis programing (ABA) demonstrated a higher rate of and more severe posttraumatic stress symptoms than autistic individuals who were not. In addition to a heightened likelihood and intensity of posttraumatic stress symptomology, this type of compliance-based intervention that focuses on repressing what is natural and normal to autistic people not surprisingly has additional mental health implications. When asked about experience with educational approaches that focused on conformity and compliance:

> *Autistic Typing—Autistic people must conform to neurotypical norms, to make others comfortable without any regard for their own feelings.… Autistic kids are subjected to terrible messaging that they are inferior. Even well-meaning people who want to help send this message in the way they speak about autism as a sum of deficits.* (Autistic Typing, July 25, 2020)
> *Patti- So as we communicate our emotions (in autistic ways), these behaviors may then be squelched, and trained out of us. The sense that mom, therapist, or society wants to fix me um—and not really seeing our personhood.* (Laurent et al., 2019, 11:17)
> *Dena—…focusing on making them indistinguishable from their peers—which means making it so that they just go along to get along—and that can result in very tragic outcomes.* (Laurent et al., 2019, 12:16)

These sentiments are congruous with a coping mechanism known as masking that is common in the autistic community. Masking refers to an elaborate process enacted by autistic individuals to "appear typical." The mask is created when individuals implicitly learn or are explicitly taught and trained to act in ways that are familiar to the general population, but not to their own natural way of being. This

includes both suppressing natural responses, such as the behaviors deemed challenging and problematic previously mentioned, and cognitively bringing forth unnatural responses. For example, some common masking strategies include mimicking others, memorization of social scripts, ignoring or resisting one's own needs and preferences, attempting to control all aspects of social situations, researching topics in order to have something to say, not letting any reactions show (being stoic), and holding in behavioral responses so as not to stand out from others. These are only examples, and it is important to note that masking is never just one of these strategies, but any combination of them. Part of masking is knowing when to tap into which strategies. Masking is a constant state of high vigilance calculation (Cassidy et al., 2018; Hull et al., 2017; Milner et al., 2019; Spinrad et al., 2004).

On the surface, masking may appear to be beneficial, as behavioral changes can be observed (e.g., decreased incidents of neurotypically defined problem behaviors). However, these positive outcomes come at the expense of mental health and burnout, and that should not be a requisite of success for autistic people. Long-term mental health implications are associated with suppressing one's true personal identity, emotional experience, emotional expression, and physiological stress responses and using constant cognitive effort to bring forth responses that are more comfortable for neurotypical people. For example, studies have documented associations with higher rates of depression (Stewart et al., 2006), anxiety (Gillott & Standen, 2007), social anxiety (Maddox & White, 2015), as well as suicidal ideation (Cassidy et al., 2014) and suicide (Hirvikoski et al., 2016).

> *Kieran—How does any non-autistic person understand what it means to suppress your entire being for an 8 hour period five days a week? What it means to hold in the pain of auditory sensitivity, aversion to sights, smells, struggling through with executive functioning problems, anxiety, stopping yourself from stimming, being forced to learn in a room, in a building that hurts you, being forced to learn in a way that is not conducive to how you learn, often taught by people who have no idea how to meet your needs, and not the time or ability to do so?* (Rose, 2018b, July 24).
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> *The Autistic OT—I masked my entire life. Laughing when a joke didn't make sense. Smiling because it was expected even if I was uncomfortable. Internalizing dysregulation to be more feminine. Restricting movement to be socially appropriate. Don't be "too much" or like anything that was not gender-normed. Be soft and quiet ….I learned quickly that loyalty was compliance. This made little sense to me. To me, a true friend could be one that disagreed with you but stuck it out to reach a mutual compromise (if applicable). This was wrong. It's something I still struggle with to this day. For most of my life, I tried to fit in and failed miserably. I would rehearse and script a million "cool" conversations just to fumble them in the moment. Dysregulation would kick in and my quirkiness would come out.* (The Autistic OT, March 2019a)
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> *Unmasked—I've realized something that concerns me a bit: Every single relationship I have is based on me pretending to be something I am not. I have only ever been who I truly am, as a very young child before it was snubbed out of me for not being "age appropriate" or acceptable behavior. So, I kind of don't feel like I have any actual friends. Well before like 6 months ago, after I had a mental collapse in the psychiatrist hospital and my neurotypical mask was blown to smithereens and is now impossible to apply again.* (Unmasked, July 10, 2020c)

While behavioral intervention methodologies and societal expectations for masking remain prevalent, in recent years, there has been a greater emphasis placed on understanding the underlying factors contributing to problematic and challenging behaviors. Furthermore, there has been greater recognition of the need to address those underlying factors as the primary areas to target for effective intervention that can actually help autistic individuals navigate their environments in school and as they transition out of school and into the real world (Prizant et al., 2006a). In order to provide this type of ethical, efficient, and sustainable support, it is imperative for clinicians to understand emotional or energy regulation as a developmental construct and then to understand its relationship to challenging behaviors.

> *Unmasked—When I feel intense emotions, it looks like pacing and nodding and rocking and tapping and flapping.* (Unmasked, July 5, 2020b)
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> *Michael John—The behavior in question was more than just a behavior to me—it lay at the very core of who I was. And I don't know why I had that instinct, but I just did. And so, it made the hurt doubly worse, because they weren't just criticizing behavior, they were criticizing the very fiber of who I was.* (Laurent et al., 2019, 10:56)
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> *Jacquelyn—By the time I'm melting down… exploding …shutting down, etc., it's too late. There are no thoughts or intentions or goals. It is a pure release of energy that has to come out in some form. I don't have control of it, and I often don't have memory of it. So trying to layer on some kind of token or reward for NOT doing it? It could be playing soccer with Leo Messi and I could not stop myself. Where I need help is understanding my profile and needs and how to buffer all that leads to that behavior or eruption of energy. I need support that is reliable and available when I can actually process and access it.* (J. Fede, personal communication, June 24, 2020)

Emotional/Energy Regulation

Simply stated, emotional regulation is a developmental process that matures and evolves over the course of an individual's life. It is the capacity to adjust one's emotional state and physiological arousal state (e.g., energy level) to meet the demands of one's social and physical environment

(Cole et al., 2004; Eisenberg & Spinrad, 2004; Fox, 1994; Grolnick et al., 1996; Kopp, 1982; Thompson, 1994). When emotional regulation is effective and successful, individuals use strategies to shift emotion and arousal states to match the characteristics of the social and physical environment in a way that supports maintaining engagement and accomplishing objectives (e.g., biobehavioral states consistent with higher energy to play and lower energy to sleep; Wolff, 1959). This match between internal state and environmental characteristics is often referred to as a well-regulated state. In contrast, when a person does not have or does not know how to utilize strategies to adaptively shift emotion and energy, they may experience an arousal level that is either too high or too low to engage successfully in activities and interactions. This mismatch between the internal energy state and the demands of the environment is experienced as emotional dysregulation (Eisenberg et al., 2003; Rothbart & Bates, 1998).

It is important to note that the ability to utilize tools and strategies to shift internal states is not an all or nothing proposition. In fact, the degree to which emotional regulation strategies are successful is often regarded along a continuum ranging from a well-regulated to states of extreme dysregulation. This continuum of regulatory states is associated with the full range of emotions and all valences of each. For example, mild dysregulation associated with happiness may present as giddiness, while mild dysregulation associated with anger may present as irritation. In contrast, extreme dysregulation for these same emotions may present as ecstasy and rage, respectively (Cole et al., 2004; Laurent & Rubin, 2004).

While emotion may be notable, it is the behavioral expressions that result from states of moderate and extreme dysregulation (i.e., significant mismatches between internal state and environmental energy demands) that are most often associated with and labeled as challenging and problematic behaviors for autistic individuals. It is well documented that autistic individuals tend to have fewer emotional regulatory strategies and therefore more regulatory challenges in relation to the expectations for same-aged peers (Mazefsky, 2015). This presentation of fewer strategies and more challenges is associated with reactive aggression and externalizing behaviors, particularly throughout childhood (Mazefsky, 2015; Richey et al., 2015; Swain et al., 2015; White et al., 2012; Wilson et al., 2013). Additionally, difficulties focusing attention, inhibiting reactions, delaying gratification, tolerating transitions, and seeking comfort in "conventional" ways during times of stress have all been consistently associated with the behavioral profile of autistic individuals (American Psychiatric Association, 2013; Baron et al., 2006; DeGangi, 2000; National Research Council, 2001). Importantly, evidence of regulatory challenges for autistic individuals is related to psychotropic prescriptions in this population. Upward of 60% of autistic children diagnosed are prescribed psychotropic medications in an effort to control strong emotional reactions, outbursts, and tantrums (Mazefsky et al., 2013). Emotional regulatory difficulties have also been documented to negatively impact upon the quality of peer interactions (Begeer et al., 2008; Glaser & Shaw, 2011).

Quantitative evidence highlights the pervasive implications of regulatory difficulties for autistic individuals. First-person accounts identifying regulatory challenges as an area where significant support is needed throughout their day and across their life span at all developmental levels validate research and elevate emotional regulation as a top education priority. The more often we listen to a wide range of the voices of autistic individuals commenting on their daily experiences, the more apparent this need becomes.

> *Neurodiverse 7-year-old boy speaking to his mother at home "on a rough day"—I'm a t-rex coming to destroy everything.* (A. W., personal communication, July 6, 2020)
> *Rose (age 11)—Overwhelm feels like I can't take it all in. What overwhelms me? A lot of people, a lot of attention…too many words….I shout…it just suddenly comes…I can't control it….Even if I tried, I can't….*(Secret Life of Rose, 2020a, April 16)
> *Unmasked—Seriously…how important is sensory regulation to y'all? Today was such a good day. I hear so many professionals call it a completely unfounded science but like, it is literally not. It is the difference between a good, engaged, receptive day and a blank staring, slow moving, completely unresponsive day. I have to regulate every single one of my emotions.* (Unmasked, July 5, 2020b)

In addition to those that can share their experiences so clearly through spoken and written communication, regulatory challenges and the need for related support are also frequently observed for individuals who are not symbolic communicators. These difficulties may present as obvious, explosive, and challenging behaviors. However, they may also present as struggling to engage in activities even when the task is preferred, becoming distressed, and requiring significant assistance and time to settle when encountering unpredictability, as well as relentlessly seeking movement and sensory input.

In order to design supports that are effective and authentically applicable to and affirming of the autistic community, it is imperative to understand the multitude of factors underlying challenges for autistic people as identified and described by them. It is also important to remember that, as neurotypical people, we can and should aim to learn and validate autistic experiences, but we also must remember that we cannot ever fully know or understand their reality.

> *Stephen—Let's talk about some risk factors for dysregulation for those of us with sensory issues. They include noisy restaurants and other places, tags on clothing, and also lighting fixtures that overly bright—and especially recessed lighting fixtures that we find commonly in ceilings. Social environments—certain social environments can also be dysregulating. Any activity where social interaction is the primary goal, rather than the activity. Executive functioning—thinking about thinking—for example, having to keep track of too many things without a schedule or something to refer to.* (Laurent et al., 2019, 05:55)
> *Dena—Just not having a plan, not having things be*

> *predictable. The assumption of knowledge that I don't just automatically have. Just not having control over my environment. And—You know—and then there is just the whole cumulative cognitive rain barrel. How much energy have I utilized from moment to moment in my day?* (Laurent et al., 2019, 06:38)

Challenges Due to Neurological Differences

While the neurology of autism is not fully understood, several differences in brain structure and function have been detailed in the literature (Bachevalier & Loveland, 2006; Ben Shalom et al., 2006; Kim et al., 2015; Swartz et al., 2013). Many of these differences have implications for the development of emotional regulation skills and one's ability to access such skills. For example, areas of the limbic system have shown less functional activation in autistic individuals compared to typically developing peers in response to fearful faces (Kim et al., 2015). A similar pattern of reduced activation of limbic system has also been demonstrated in response to happy faces (Kim et al., 2015). These varying activation patterns among autistic samples compared to neurotypical samples suggest different intake and processing of social and emotional experiences at a neural level, which could, in turn, influence social learning and social cognition. These differences could also potentially contribute to challenges identifying emotional reactions and experiences and physiological changes in the body. This phenomenon is known as alexithymia. It is the subject of a growing body of research pertaining to the autistic population, and it does appear to be grounded in neurological differences as well as social learning differences characteristic of autism (e.g., socialization of emotional expression; Torrado et al., 2017).

> *Unmasked—I've realized that for alot of autistic people, we don't have words for our experience. There are many things I didn't understand to be something I felt until it was described by someone else. Until I read about alexithymia (the difficulty recognizing and making sense of emotions.) I didn't know I have it. Many (many!) Autistics experience alexithymia. Is it any surprise that Autistics, who often struggle with word access in general, may struggle with accessing words to describe emotions? Alexithymia is the inability to identify and describe the feelings of oneself or others. This may be a sometimes thing, it may be a constant, but it is a really striking experience. The feelings exist, the feelings are present and impactful, but we may not be able to decipher what those feelings are.* (Unmasked, July 23, 2020d)

Differences in Attentional Preference, Cognitive Learning Style, and Social Communication

Development of emotional regulatory abilities in typically developing individuals is largely a socialized process (DeGangi, 2000; Fox, 1994; Tronick, 1989). Children and individuals register events and information in their environment and react to it (e.g., emotion expression or emotional regulation strategy), and that reaction is subject to feedback from others. Then, based upon the feedback received, the child/individual modifies their reaction. For this learning process to work, the individual must be focused on and responsive to the social environment. It is well documented that autistic individuals demonstrate strong attentional preferences for objects as opposed to people or other social stimuli (Koenig et al., 2000). This difference, then, may have implications in the development of emotional regulation, because autistic individuals are not focusing on human or social stimuli to the same degree as neurotypical peers. It has been found, for example, that autistic individuals' cognitive style differences correlate with decreased attention to others' actions, feelings, and intentions (Prizant et al., 2006b). Likewise, these social learning differences are related to regulatory profiles that are consistent with less sophisticated strategies developmentally and reduced ability to modify emotional reactions and regulatory strategies in response to feedback of others (Bachevalier & Loveland, 2006; Gulsrud et al., 2010; Konstantareas & Stewart, 2006; Raver, 1996).

Further differences related to an individual's expressive and receptive communicative means have significant implications for the socialization of emotional expression and emotional regulatory strategy acquisition. For example, social communication differences may impact a child's ability to understand and acquire emotion vocabulary in the context of naturally occurring interactions as well as their ability to use language to request regulating assistance from partners. This may present as limited vocabulary, but also in using less conventional means to express experiences, such as echolalia.

> *Chloe—…scripts serve meaning, there's a purpose. I'm sure many are feeling the unpredictability that COVID-19 brought with it. Today I said, "The sky is falling!" What I was trying hard to say is hey, wow things are different now than 5 months earlier. There's lots of unpredictability and I'm not sure about it.* (C. Rothschild, personal communication, July 17, 2020)

Differences in Sensory Processing and Physiological Differences

Part of the autistic profile consists of underlying sensory processing differences. Hyper- and hyposensitivities to sensory information are included as part of the diagnostic criteria for autism. These sensory processing differences present both as responses to environmental stimuli (e.g., visual, tactile, auditory, gustatory, olfactory, vestibular, proprioceptive) and internal sensations, (interoception—perception of hunger, thirst, pain, etc.). Interoceptive processing and sensory processing differences have both been indicated as risk factors for dysregulation and increased anxiety (Di Tella et al., 2020; Morie et al., 2019; Trevisan et al., 2019). In fact, elevated cortisol levels have been associated with increased sensory sensitivity (Corbett et al., 2009). Similar patterns of

heightened physiological responses (e.g., increased cortisol peak levels and duration) have been noted in autistic individuals when compared to peers particularly in response to novel environments and stressful conditions (Corbett et al., 2006; Spratt et al., 2012). The evidence of heightened sympathetic nervous system response in the physiological profiles of autistic individuals paired with the research documenting differences such as significantly increased resting heart rates when compared to same-aged peers (Bölte et al., 2008; Thapa et al., 2019) is indicative of a bias toward strong flight or fight and other stress responses. Additional studies exploring the influence of the autonomic nervous system have found reduced heart rate variability during stressful conditions (Thapa et al., 2019). This presentation is consistent with decreased parasympathetic activity, which is known to facilitate the stress recovery response.

> *Kieran—Surrounded by noise; screaming children in the playground, shouting children, singing children, musical instruments, banging and clashing the general commotion of the classroom; and over the top, the dumpf dumpf—dumpf of my heart in my ears and in my chest. The strip lights overhead, flickering constantly in pulsing waves, each one shooting through my eyes and down through my body; I can physically feel each pulse humming and vibrating. A vast array of colors and patterns on the brightly colored walls, covered by brightly colored work. The sun glaring through 40-year-old grimy windows, diffracted around the room, while a billion dust particles dance captivatingly, confusing my already overwhelmed eyes…. Suppressing my reaction to all of this, the urge to scream and scream till I explode—wanting it all to go away….*(Rose, 2018a, May 21).
> *Kristy—When we are exhausted, our cognitive functioning, our executive functioning, our communication, our sensory processing, our being is extremely compromised, and we risk tipping over into burnout or even trauma if we push ourselves too hard.… Sometimes,…we have to make that very difficult call around understanding and nurturing a different neurobiology; an autistic neurobiology.* (Forbes, June 25, 2020b)

These differences are significant risk factors that predispose autistic individuals for dysregulation. At a most basic level, autistic people demonstrate many physiological differences that prime them for spikey energy profiles and make mismatches (dysregulation) more likely. Regulation challenges have significant implications for being able to successfully fulfill desired roles and engage in productive, meaningful routines, regardless of developmental level, chronological age, and symbolic communication capacity. For example, a young child may be excluded from class activities due to disruptive behaviors stemming from dysregulation. In adulthood, research highlights this same behavior pattern adversely affecting employability. Challenges maintaining focus, coping with unexpected change, and reacting in "socially appropriate ways" to misunderstandings in the workplace are all highlighted as major factors for unemployment among autistic people. Rates of unemployment for this population are estimated to be between 85% and 87% (Hensel, 2017; Sarrett, 2017) despite close to 90% of autistic adults reporting that they want to work and/or further their education (Hendricks & Wehman, 2009). Additionally, challenges in emotional regulation have been linked to diminished quality of life in adulthood (Dijkhuis et al., 2017).

It is apparent from this discussion of the behavioral presentations associated with regulatory difficulties the underlying risk factors predisposing autistic individuals for regulatory challenges and the functional implications of frequent dysregulation that the need for regulatory support is crucial. Additionally, the efficacy of such support has far-reaching implications in terms of quality of life and active engagement. It is also apparent that interventions focused solely on the resulting behavioral expression of dysregulation (repetitive behaviors, challenging behaviors, disruptive behaviors, etc.) are ill-conceived and inappropriate when it comes to helping mitigate underlying factors. In several cases, they are also unethical and, in extreme cases, abusive. These traditional ways of managing behavior according to neurotypical standards of success (e.g., "sitting still," "quiet hands," "quiet voice") are often ineffective and unethical (Wilkenfeld & McCarthy, 2020). They are also counterproductive to supporting real, authentic engagement in a way that is respectful to and affirming of autistic learners, sustainable across the life span, and leads to understanding and the ability to self-advocate as best understood from firsthand accounts.

> *The Autistic OT—Compliance may be measurable, but the long-term consequences are often dire. Disabled people are 8x more likely to be sexually assaulted. Autistics are more likely to develop trauma symptomology if they participate in compliance-based behavioral programs.* (The Autistic OT, April 3, 2019c)
> *Unmasked—I'm sure I can get better, but for now this is the support I need. Instead of someone just "exposing" me to new people and crowds, I am able to say exactly why I don't like those things, and it is easier to deal with them by recognizing my own body telling me when to stop. Instead of ignoring my signals because I'll get a cookie if I do this, I am learning to develop my OWN coping mechanisms. At age 24. Because I wasn't taught as a child. Now I'm having to relearn everything the way I am able.* (Unmasked, June 22, 2020a)
> *Chris—Far too many professionals' goals for autistic children: After enough compliance therapy, the child will be indistinguishable from their peers. It's one thing to help an autistic child with their difficulties so they can reach the levels of children *without* such difficulties. Because, that's about capability, and not about personality, expression, or self-advocacy. (It also leaves room to encourage the child's strengths, as well as addressing areas for development.) But, I *despise* the phrase "indistinguishable from their peers" because it means something very, very different.* (Bonnello, January 15, 2020)

In order to design effective regulatory supports and interventions for autistic children and individuals, programming and intervention must be predicated on areas of need, consider their unique learning styles, and respect neurophysiologically based differences detailed above. There must be a focus on facilitating the learning process that is regulation to foster a sense of empowerment, and all of this must be carried out through dignified processes and methods. Understanding emotional/energy regulation as a developmental construct and incorporating the perspectives of autistic individuals are two cornerstones in the foundation of this process.

Energy Versus Emotion: Autistic Perspective

We have already discussed the importance of engaging the community in discussions about their needs and the types of interventions utilized to meet those needs. We have also noted the critical need to design and use tools and strategies that are appropriate for the learner based on their developmental level, communication style, learning style, and profile in general. It is also imperative that any form of support is respectful of natural autistic expression so that we do not end up contributing the building blocks or foundation for a mask. Engaging the community, of course, helps us to better design programming and supports that are respectful in honoring autistic people and that are accessible to the community. It also acts as a check on whether we are designing and implementing programs aimed at the goals and outcomes that are important and high priority needs per the community. We know from the autistic community that behavioral focused plans are not effective nor sustainable in the long run because these plans tend to explicitly teach an autistic person how to look like their neurotypical peers. The goals of these plans often do not resonate with the autistic student, but with neurotypical parents and educators, with good intentions, but who are biased by their own preferred outcomes.

Emotional expression is one such outcome on which neurotypical people tend to become hyperfocused. They want to support autistic people to be able to access emotion-related vocabulary and terms, because they understand it as an extremely important developmental milestone. It is true that this skill set is linked to being able to control emotions as opposed to being at the mercy of them (Grolnick et al., 1996; Zimmerman, 2000), and it is, therefore, critical to the process of regulation. Emotional expression and understanding are also regarded as central to basic interactions with others and for forming and maintaining relationships (Tronick, 1989). Therefore, this focus is understandable; however, it is not informed by the autistic perspective nor does it take into account a robust understanding of regulation. There is nothing wrong with emotion, nor is it wrong to try to support autistic people to be able to engage in understanding and utilizing these concepts. However, challenge arises when the neurotypical conceptualization of emotion is not accessible to an autistic person due to the abstract nature of the concepts. This is often compounded by social learning and processing differences (Fitzgerald & Bellgrove, 2006; Jahromi et al., 2012; Koenig et al., 2000; Maljaars et al., 2011; Mazefsky et al., 2013). Additional factors may impede the concept of emotion from resonating with an autistic individual. For example, there are many negative and positive connotations associated with emotional valences. States of being are neither positive nor negative on their own, but current programming tends to teach happy as a desirable/good state and emotional states like mad or sad as undesirable/bad states. This educational focus tends to promote the notion that individuals should consistently attempt to move out of negative emotional states and into positive ones even when it may not be adaptive to do so (Dunn Baron & Curtis, 2012; Kuypers, 2011). This blend of emotion, abstraction, and social construction combined with the fact that it is taught in the social context and layered with the negative and positive connotations associated with emotional labels is extremely challenging. Thus, it often leads to autistic children and adults reporting they are happy regardless of their true state, because it is too confusing or impossible to process and deduce and they know that any other answer may be perceived as "bad." The autistic community is clear that faking something as human as emotional expression for years of one's life can easily form one very fatiguing element of a mask and is something education should aim to avoid.

> *Jacquelyn—I have never been able to identify my own emotions. I can feel when something is different. I know when something is happening to the energy inside of me—if it is pulsing or surging or very still —but how that can possibly tie to some word like happy or angry or both? I have no clue. Sure, I can learn to say that I am sad or happy or mad or parrot back what you tell me I look like I am, but it will give you no indication of my actual state.* (Jacquelyn Fede, personal communication, July 22, 2020)
>
> *Ama—Basically focusing on energy for regulation affects everything I do, and everything I experience. Emotion is just a tiny part of that from my perspective, so trying to regulate by focusing on emotion is counterproductive, because it leaves so much out that I *can't* leave out, *and* function at the same time.* (Ama L., personal communication, July 14, 2020)
>
> *Mom of 7-year-old autistic boy—I think it's the only thing he gets…. I sort of had it wrong dealing with emotion. Emotions are too hard.* (A. W., personal communication, April 23, 2020)

Of course, difficulty understanding and expressing emotion is not universal in the autistic community. And for those with whom emotion resonates its use can be encouraged and supported for the purpose of facilitating the development of regulatory skills. However, it is not the only option to support autistic people in learning regulatory skills. Regulation, that is, all the ways by which one shifts their energy to match the requirements of the environment around them, is a core feature of one's personhood. The

way one perceives the world and the way one feels are also central to their identity and sense of self. Thus, it is imperative that education and support in these areas do not aim to erase what is natural and replace it with terminology and actions that are in sync with what neurotypical peers would expect or do. One of the simplest things we can do, which is clear in listening to many different autistic voices, is to use the concept of energy instead of or in combination with emotion. As many in the autistic community acknowledge, emotion words are difficult for them to access, especially during times of heightened arousal. Energy is a more concrete and observable concept and may be easier to learn and more relatable to autistic individuals.

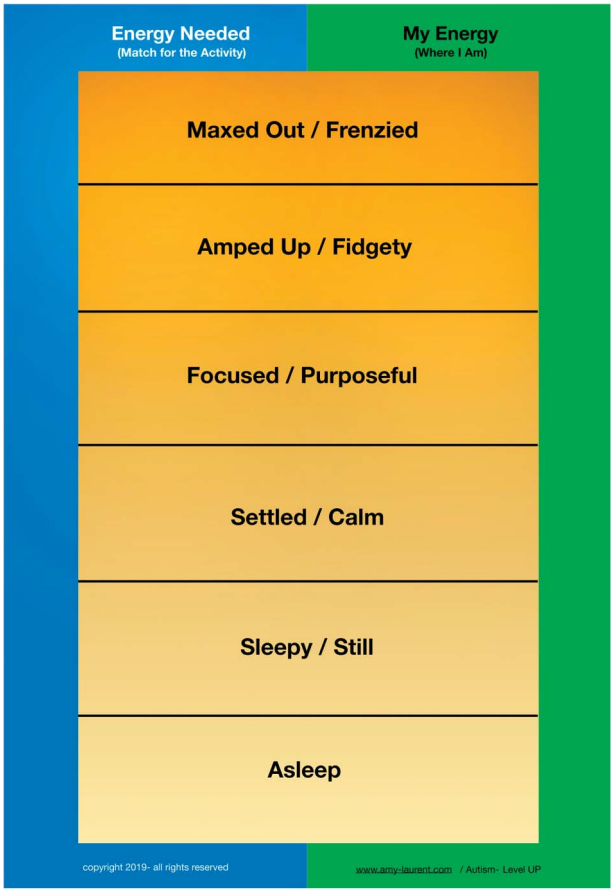
> *Kristy—Words, verbal language is not my first language. It is not my native tongue. Energy is. Presence is. Feeling is. I don't feel with just my emotions. I feel with my entire being, what is seen of me, and what is unseen. I experience BEING with my entire physical, ethereal, spiritual, emotional, mental, energetic, expansive existence.* (Forbes, May 28, 2020a)
>
> *Jacquelyn—The use of energy instead of emotion has helped me tremendously in seeking out support and help when I need it. Before, if something felt wrong, I would do everything in my power not to let it show at all, because I knew that if someone noticed something was off, they might ask me to tell them what's wrong and I could never do that. Knowing I may be asked to describe my emotional state was like a language barrier to seeking help. Energy is true to my actual experience. It makes sense to me, it is accessible to me and it is true to me, so it works.* (J. Fede, personal communication, July 17, 2020)
>
> *Kaylen—I really like focusing on energy instead of emotion for regulation. It's still new to me so I'm still learning, but it's often easier to monitor energy levels than figure out what emotion I'm feeling. Plus, I don't know that there's an emotion for every state/situation. For example, which emotions are associated with mental fatigue, hunger, or an overstimulating environment? I don't know? But I do know that things like executive functioning or effective communication start to go out the window if I don't take enough breaks, move around, eat before I'm starving, get to a quieter place, etc. I may end up feeling frustrated or something, but that isn't the real issue. The actual problem is that I depleted my energy and I don't have much to work with at that point. Emotions also aren't as reliable because I can feel happy and enjoy something, but still end up completely drained during or after that situation. And then I need time to recover.* (K. Randall, personal communication, July 2, 2020)

This shift to an energy focus is also supported by the developmental literature. As previously stated, the relationship between emotions and physiological arousal levels is intricately intertwined (Thompson, 2011) and the regulation or shifting of both emotion and physiological arousal levels is discussed as central to the process of emotional regulation. Therefore, in an attempt support the development of meaningful tools to support regulation, they must be designed with autistic learning styles as a key consideration for accessibility. One way to do this is to remove the language of emotion and to focus on physiological arousal levels and energy states. Wolff (1959) first categorized these biobehavioral states into observable indices. It is generally agreed upon that there are six to eight states that range from deep sleep (very low arousal) to extremely dysregulated (very high arousal; Brazelton & Cramer, 1990; Prizant et al., 2006b; Rainforth, 1982; Wolff, 1959) The removal of emotion words and a focus on energy and arousal states allow us to better avoid the pitfall of labeling states as either negative or positive; good or bad. It moves us forward, toward understanding regulation as a goodness of fit between one's internal energy state and the energy that is needed for participation in any given environment and/or task, where well-regulated is not one specific state, but a match between person and environment.

Based upon the perspective gained from engaging the autistic community and validation of the developmental literature, the authors developed the Energy Meter (see Figure 1), which is designed to help determine and introduce in a cognitive and visual way the concept of energy and energy matches and mismatches to support regulation. To level it up from its biobehavioral origins, we labeled each of these six states in more culturally relevant and neutral terms.

The developmental literature is clear that each of these six states, no matter how they are labeled, is adaptive and germane to the daily human experience. There is not a "target" state or a preferred state that humans should aim to maintain. If we are successful in the navigation of our day from a regulatory perspective, we shift through these states adaptively to meet the demands of the energy needed in the environments and activities in which we engage. Sleepy and still is a good match before settling into bed for the night, while amped up and fidgety is adaptive at the start of a road race. This tool is also designed to provide a systematic way to denote when energy matches (e.g., a well-regulated state) and energy mismatches (e.g., a dysregulated state) occur between the activity and the person. The left side of the support (i.e., Energy Needed) is used to record the energy needed to adaptively engage in the current activity or environment, and the right side (i.e., My Energy) is used to indicate the energy level currently being experienced by the individual. When the arrows align, the individual's energy matches the energy needed, that is, the individual is well regulated, and no additional support is likely needed. However, when the arrows indicate a discrepancy between energy needed to function adaptively and current individual energy levels, for example, dysregulation, the use of regulatory strategies will be critical to supporting engagement. For example, if a school-based SLP is working to support a student's engagement in a whole class literacy lesson and the student is demonstrating actions consistent with "amped up/fidgety" energy, but the Energy Needed for active engagement is "focused/purposeful," the SLP can use the

Figure 1. The Energy Meter (Laurent & Fede, 2019a). Copyright © 2019 Autism Level Up! Figure courtesy of the authors. Retrieved from http://autismlevelup.com/energy-meter/



Energy Meter as a tool to provide the student with concrete visual feedback of the energy mismatch (e.g., the arrows on left and right sides of the meter are not aligned) and offer regulatory strategies to help power down the student's energy.

> *Robyn—Pinpointing emotions in the moment can be very difficult but it's fairly easy for me to identify my energy level & guess the energy level needed for the current activity. Then the amount of energy between the two is easier to figure out the "tension" then an X, Y axis with four quadrants I can use energy, tension to label an emotion. But energy alone can help me navigate a day & understand my frustration.* (R. Allison, personal communication, July 14, 2020)

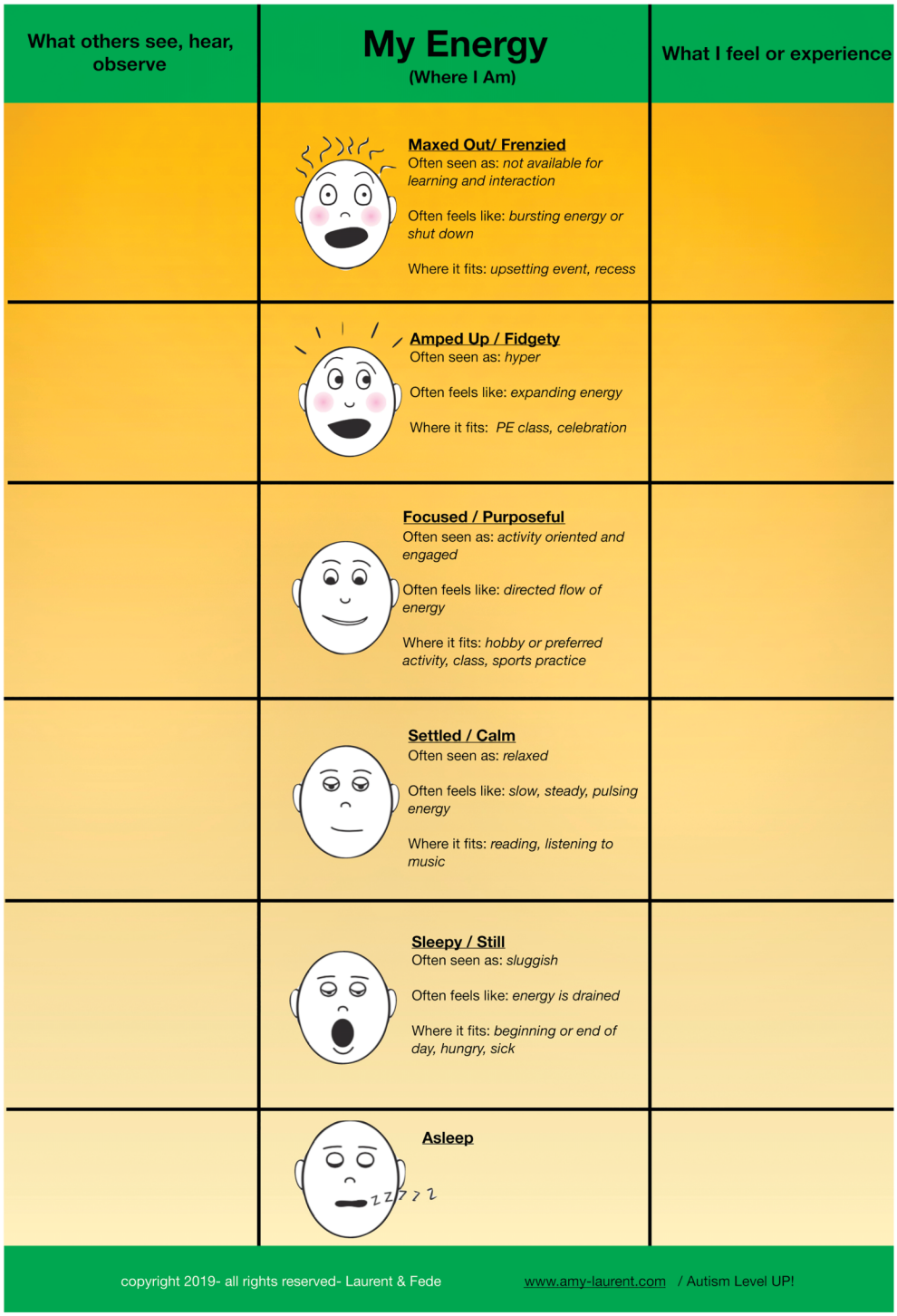
Reading Energy

Effective use of the Energy Meter is incumbent upon an accurate understanding of energy in relation to regulation and also upon an accurate understanding of the experience and expression of energy for an individual person. We must be able to accurately identify the energy state of those we support in order to make valid inferences as to the existence and degree of energy mismatch (i.e., dysregulation). As previously highlighted, autistic individuals' risk factors, which increase their susceptibility to dysregulation, can vary widely and they are subjected to risk factors that are not common among neurotypical people. Therefore, it stands to reason that their experience and expression of these energy states may also vary widely and be unexpected to neurotypical people. As such, it is imperative that the unique experiences of an individual's energy be taken into account. To facilitate this process, we designed "My Energy" (see Figure 2) to help capture critical information related to how the individual experiences different energy levels (e.g., what it feels like to the person) and how their experiences may appear to others (e.g., what it looks like or what tends to happen that is observable). Just as stated for the design of The Energy Meter, if possible, engaging the autistic individual in the completion of this tool is highly desirable. Many autistic individuals are quick to comment that their experiences are often not what they outwardly appear to others.

> *Rose (age 11)—A meltdown feels overwhelmed. It looks angry, but it doesn't feel angry. Feels like overwhelm … like so much going on around me … . Kind of like a volcano … . It all just comes out all at once … .* (Secret Life of Rose, 2020b, April 21, 2020)
>
> *Patti—My internal state is not really reflected in a way that neurotypical person might recognize as joy. Umm.… But I will say, a lot of it can be things like hand flapping and um.… like the bouncing and swaying —things like that.* (Laurent et al., 2019, 08:20)
>
> *Jess—This approach has also really helped me to recognize when I need to self-regulate! I've always struggled to recognize emotional signs of overwhelm—I have all the "tools," I know how to use strategies from CBT and ACT but always needed my husband to point out when I needed to use them. If he didn't, I wouldn't realize what was happening until it was too late and then it would become a whole big thing! Since I started to focus more on physiological signs though (my energy levels being the main indicator) I've found it much easier to self-regulate before I get to that point.* (Jess, personal communication, July 23, 2020)

Coming at energy or emotional expression from this perspective is empowering. To begin this process, SLP's may introduce My Energy by commenting on a conversational individual's observable behaviors during an activity (e.g., "To me it looks like your energy is focused and purposeful. I see you doodling on your paper and rocking in your chair. And, I heard you ask a question about the work you have been assigned. Do you think you're focused? How does that feel in your body? I want to make sure I understand and remember, so let's write this down"). This type of conversation can be repeated and reviewed until the support is complete and the understanding of energy level differences is clearly defined for the individual. Consider the difference for autistic people between being asked to show, write, or tell their partners what different energy states feel like to them, as well as how they think these states look to others,

Figure 2. My Energy (Laurent & Fede, 2019b). Copyright © 2019 Autism Level Up! Figure courtesy of the authors. Retrieved from http://autismlevelup.com/my-energy/



and being told what their expression of each energy or emotion state should look like. The former sets a foundation for self-awareness, understanding, and self-advocacy. The latter is not truly supportive as it contributes to masking, enormous cognitive load, and a completely unsustainable and damaging expectation for navigating one's day. This simple switch from controlling another's expression of energy to learning another's expression of energy goes much further

inbuilding trust between partners and in providing real support.

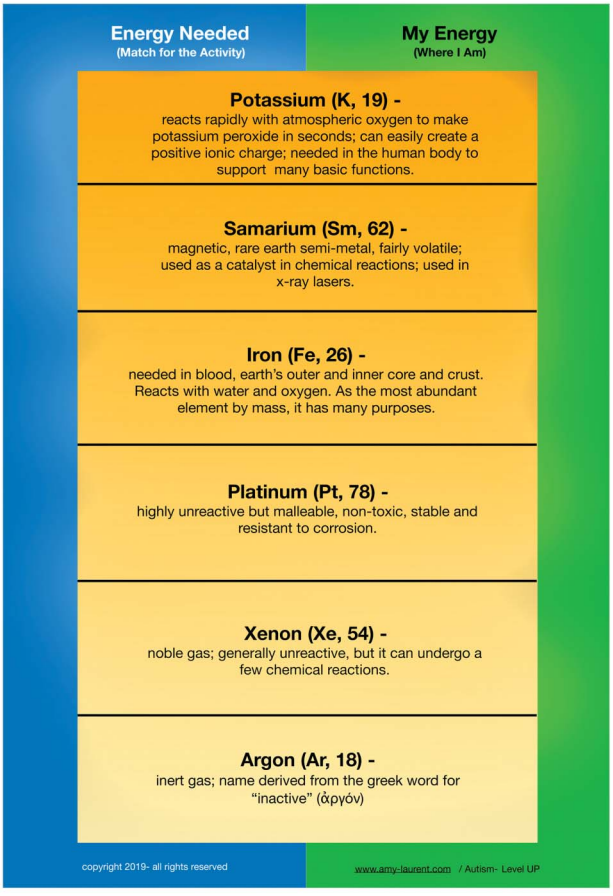
For all of these reasons, the participation of the autistic person is ideal; however, if the individual is not able to contribute to the form in a traditional way (e.g., by talking through or writing their experiences), the team surrounding that child or individual can use the tool as a framework to structure their observations in order to begin forming an understanding of the autistic person's experience. In this scenario, ideally several team members and/or family members who know the individual well are encouraged to share their perspectives so a consensus can be formed. This provides much needed consistent interpretation of the person's behavioral signs and signals associated with energy levels.

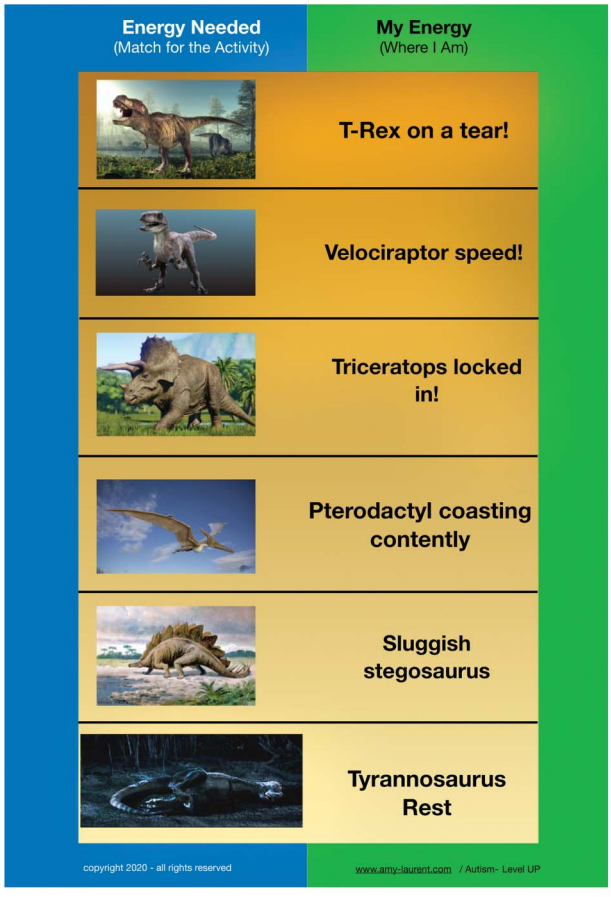
Regardless of the process by which the form is completed, the completed My Energy form can then be used to modify and adapt the Energy Meter, described above, as well as incorporate relevant interests and preferred terminology. It is always encouraged to include the autistic person in design decisions if they are developmentally able to engage in such processes. If an autistic learner cannot contribute in any way, it is best to have staff, parents, carers, and those who know the person best discuss and decide what terms and how many would be appropriate to support the individual. For examples of the Energy Meter adaptations, see Figure 3. It is also possible to simplify the scale from six states to three or four so that fewer choices are available and present in the field of vision. This is a support that can easily be adapted from individual to individual and within the same individual over the course of their development.

The individualization of energy can provide a common ground and a foundation of mutual understanding. It may minimize some elements of masking, and it will build greater trust between partners when educators and parents set out to learn how autistic people experience the world and express themselves and then use that knowledge as an ally in their support of the autistic student rather than identifying those differences in expression or experiences as goal areas for improvement.

> *Neurodiverse mom of 7-year-old neurodiverse boy reflecting on his use of a Dinosaur adapted energy meter. "It lets (him) pick energy that isn't related to emotions.*

Figure 3. Individualized, adaptations of The Energy Meter (Laurent & Fede, 2019a). Copyright © 2019 and 2020 Autism Level Up! Figure courtesy of the authors. Retrieved from http://autismlevelup.com/energy-meter/





> *Due to all the PBIS stuff at school, he thought certain ones were bad or wrong. Now I say hmmm, which Dino suit are you wearing (sort of Wild Kratts style)—then we discuss if the Dinos adaptations are right for the activity that we are doing. If not, we do activities to change it."* (A. W., personal communication, April 2, 2020).
> *Follow up on the Dino meter—I can look at him and say you look like a T. rex right now and he will attempt an activity to change. So, the other morning, he comes down all out of sorts. I said wow that's an impressive T. rex suit. He says oh shoot hold on. Runs back upstairs, probably to suck his thumb and cuddle with his giant bear. Then he comes downstairs and says well I changed Dino suits.* (A. W., personal communication, July 22, 2020)

This framework recognizes, honors, and supports authentic ways of expressing and experiencing various energy levels. It also acknowledges that autistic individuals often experience dysregulation and mismatches in energy and that this dysregulation requires developmentally grounded support. It is our regulatory skills and strategies that enable us to make these shifts and also help support our ability to maintain our needed energy in any given environment.

Building Capacity

When designing supports, it is important to consider the types of strategies that will facilitate successful navigation of daily challenges and initiation and maintenance of active engagement. These strategies can be conceptualized in a number of ways. One of the most common distinctions is between self-regulation and mutual regulation strategies. Self-regulation strategies are those that an individual employs on their own to help navigate their days through obstacles like transitions, delayed gratification, unpredictable or unplanned events, and others (Prizant et al., 2006b; Tronick, 1989). Mutual regulation strategies are those that are employed by or with the guidance, assistance, or facilitation of others. They may involve responding to assistance offered by others, but also include asking for assistance. Many factors influence the effectiveness of both self- and mutual regulation strategies, but it is widely held that individuals who are able to use both are better equipped to attain and maintain a well-regulated state rather than relying solely on one type of strategy (Sameroff & Fiese, 1990; Tronick, 1989). When a balance exists, individuals are able to navigate their days more effectively because some situations will require independent strategies whereas others may necessitate assistance from others. Thus, the burden does not fall entirely on the person or on their partners, who may not always be available to the person. Ensuring that an autistic individual can utilize both types of strategies should be a consideration in addressing their regulatory support.

Additionally, when designing a program to support the acquisition of new regulatory strategies, it is imperative to consider the developmental abilities of the learner and to match those abilities with the types of skills being introduced. Regulatory strategies are often categorized into sensory-motor/behavioral strategies, language-based strategies, and metacognitive strategies (Prizant et al., 2006b; Zimmerman, 2000). From a developmental standpoint, sensory-motor strategies are the first to develop and are accessible in some way to all learners. Humans start to use such strategies in infancy and employ them into adulthood and throughout the entirety of their lives. They are strategies that provide sensory or motoric input and can either increase or decrease arousal levels depending on the sensory profile and motoric preferences and skills of an individual. Examples range from sucking on one's thumb, holding a comfort object and averting one's gaze to tensing one's body, going for a run, or working at a standing desk.

Language-based strategies are accessible to those that understand and use symbolic forms of communication. Language strategies are often referred to as informational strategies, because symbolic systems such as schedules and timers provide information that help to increase predictability in the activities and the environment. In addition to these types of systems that are often used receptively to convey information, many language-based strategies are expressive in nature. Such strategies refer to being able to request help and other assistance, as well as being able to express emotion or arousal state. Finally, metacognitive strategies are accessible to those individuals who demonstrate the cognitive capacity and symbolic thinking to navigate their environments drawing upon and utilizing past experiences and knowledge (Zimmerman, 2000). In a typically developing population, this skill develops around 8 years of age and will, therefore, not be an appropriate goal or strategy for anyone chronologically younger than 8 years. This type of reflection is abstract and complex—it may be used in the moment to access past experiences and decide what things worked or did not, or it can be used outside of the actual event or task, through reflection to plan for future events.

It is clear that developmental abilities of an individual are critical to consider when determining which strategies may be effective and appropriate to help support the development of a regulation plan. Fluctuation in the ability to access a range of regulatory strategies is likely, particularly if one is developmentally young, and is also important for those providing regulatory supports to consider. Access to and use of strategies may fluctuate due to changes in arousal level and stress. The higher one's arousal level or stress, the less likely one is to be able to access regulatory skills, particularly those that require more cognitive processing. Recall, again, that autistic individuals are more likely to idle at more extreme arousal levels (e.g., amped up or sleepy and still). They are also more likely to experience "spiky" profiles, moving rapidly, and intensely between more extreme states. Language-based regulation strategies are particularly susceptible to this variability in arousal. Speech-language pathologists are in a unique position to help ensure accessibility of communication supports to help alleviate challenges that arise when words are not accessible. Being armed with an

understanding of regulation and how it is both affected by and influencing language, communication, and speech will assist speech-language pathologists in being able to offer more targeted strategies to support engagement through energy regulation. Ensuring that an individual is capable of using and has access to multimodal communication at their appropriate developmental level is critical. The importance of developing Augmentative Alternative Communication Systems, as well as scaffolding the development of easily readable nonverbal signals (the use of gestures, objects, etc., is highlighted in the experiences of autistic individuals.

> *Chloe—Typing helps me. Knowing that I have an alternate way to communicate and have my voice heard, even if I'm feeling dysregulated has been so helpful for me. I can write, type, text, or use my device to express myself and advocate even when things are hard. One of my staff who supports me will even offer me her phone with notes opened since she knows typing can be easier for me.* (C. Rothschild, personal communication, July 7, 2020)
>
> *Unmasked—Communication is the MOST important skill. It would make literally everything easier. My life is easier now that I have "I don't know you." And "go away." Programmed onto my phone because I can't say it verbally for some reason.* (Unmasked, June 22, 2020a)
>
> *Autistic OT—I am not able to speak words during times of intense stress, sensory dysregulation, or fatigue. I can, however, communicate. Sign, behavior, text, etc. Occasionally, I will not speak as a preventative measure. For example, when I travel by air, I write index cards for people I need to interact with such as TSA and the flight attendants. I also have pen + notebook available.* (The Autistic OT, October 6, 2019b)

It is important to note that regulatory strategies employed by the individual may also fluctuate based upon preferences in the moment, the availability of supports, and also the availability of partners. Therefore, it is critical that partners who are supporting regulatory development plan to support a continuum of developmental abilities (e.g., sensory, language, and metacognitive) as appropriate for the individual.

> *Kristy—Asking me to hone in with my visual sensory system and my auditory system all at once on the one, same thing is only going to work for me for all of about 5 minutes. I need to look around, move my body in order to assist the process of information settling. Sitting still feels like an ant marathon firing off inside my being, movement calms me, regulates me, keeps me centered. SO, if you want me to hear you, let me scribble while you talk, look around the room while you talk, rock while you talk, let me use a stim toy or have access to a comforter. But also, as the adult, please implement other accommodations so that if I do veer off in my focus, I can come back to the information in another way. Write it in dot points on the board. Check in with me quietly and privately to keep me on track or ask how you can help me. Allow me extra time for processing. Remember my brain works in a way that is different to yours.* (Forbes, July 8, 2020c)

One tool designed to help determine potential new self-regulation strategies and mutual regulation strategies is The Regulator 2.0 (see Figure 4). This tool is designed to support autistic individuals and their partners understand which strategies are feasible to employ, most comfortable and enjoyable to use, and how they influence the person's energy. If the individual has the symbolic communicative capacity to actively contribute to this form, they should be encouraged to do so. However, like the other tools discussed, it can be used as a framework to guide observations for individuals who are not yet communicating symbolically. For example, family and team members can create opportunities for a young child to engage in the activities listed on The Regulator 2.0. In turn, they can observe how the individual engages in the activities/strategies and use the structure of the form to reflect on the influence of the activity on the young person's energy and their desire to participate in that activity (e.g., chewing gum settles energy and is sought after by the individual). If being completed observationally, this support, too, would require consensus on "My Energy" by partners before observations could be made regarding how the person's energy is being influenced by these various strategies. Even for autistic individuals who can administer and fill out The Regulator 2.0 on their own, helping to ensure they have reflected on their own energy first by completing "My Energy" is encouraged! When considering new regulatory strategies, it is important to make sure activities that both increase and decrease energy levels are prioritized and that the strategies are desirable to the person. Desirability will increase the likelihood that the individual may use the strategy independently at some point in the future. This tool focuses on sensory motor strategies as these are often the most accessible to autistic individuals regardless of their cognitive and symbolic communication abilities, especially when they are more dysregulated. However, a similar framework could be used to introduce and evaluate language-based strategies.

What We Know

Autistic brains are different, so naturally, we must think differently about how we provide meaningful support and what that looks like. Our aims must center upon learning the profile and experience of the autistic individual, helping them to learn their own profile and needs, and implementing programs that foster the transfer of energy regulation skills through explicit affirmation and teaching. This is counter to methods that aim to change the person, extinguish external behaviors, and force compliance to norms, those that lead to masking and unsustainable or ineffective strategies for real-world applications. Importantly, community needs should set the standards for what outcomes are desirable and goal-worthy. The neurotypical assessments of what contributes to the quality of life, or what success

Figure 4. The Regulator 2.0 (Laurent & Fede, 2019c). Copyright © 2019 Autism Level Up! Figure courtesy of the authors. Retrieved from http://autismlevelup.com/the-regulator-2-0/

Sensory System	Tools and Strategies	How it changes my energy…			How much I like it…		
		Soothing	Neutral	Alerting	Yuck	Okay	Awesome
Vestibular (movement/position in space)	*Jump up and down*						
	Touch toes / stretch						
	Spin or dance						
	Sprint or run up stairs						
	Rock						
	Go for a walk						
	Flap hands						
	Swing						
Proprioceptive (muscle and joint input; position/pressure… often considered the universal regulator - same input can increase or decrease arousal)	*Ask for tight hug from trusted person*						
	Carry heavy items						
	Stomp feet						
	Use weighted blanket or hug vest						
	Play tug-of-war						
	Take deep breaths						
	Do chair push-ups						
	Squeeze putty, play doh, stress ball						
	Squeeze hands						
	Use a chewy						
	Suck on a straw or water bottle						
Tactile (touch)	*Ask for a massage from trusted person*						
	Stroke preferred fabric/surface						
	Tap fingers on table/desk/leg						
	Use koosh ball or textured fidget						
	Use texture bins						
	Hold stuffed animals						
	Shuffle deck of cards						
	Clap hands / give high five						
	Finger paint, color, or draw						
	Rub worry stone or smooth object						

means, for example, may be very different from the autistic evaluation of these outcomes. The discrepancy between the two different interpretations means that if professionals strive to shape autistic students based on neurotypical standards and do this successfully, they are contributing to building the mask. It does autistic people no good to be stripped of any natural coping mechanisms, armed only with tools and strategies that are unnatural for them and only aware of their needs insofar as those needs are not valid.

Using the framework presented here and immersing oneself in the experiences of the autistic community will help to facilitate the conceptualization of more reliable, valid, and effective supports, goal-setting, and programming overall. True community collaboration means a constant back-and-forth dialogue (the irony of the autistic person teaching this to the NT speech humans…) between the autistic people, families, educators, support staff, researchers, and all relevant stakeholders. More than that, though, it means that, among all of these groups, autistic people who have gone through their educational careers are considered the key informants. It means that all of these stakeholders commit to continually learning from one another in order to evolve and adjust our methods, processes, polices, programs, tools, and supports to reflect our most current understanding. It means having the infrastructure, trust, and communication in place so that new research findings that align with community experiences and needs are presented to autistic people, their families, policy makers, and educators in accessible terms and considering the limitations, restrictions, and feasibility of implementation for all involved so that effective innovations are actually translated into practice that supports progress on appropriate indicators of real community needs.

Future Directions

In addition to its primary focus on the vital importance of collaboration with the autistic community in order to generate reliable, valid, and authentic supports, this clinical focus article describes an evidenced-based practice for supporting regulation of autistic individuals that is the work of the authors in collaboration with the community. It is important to acknowledge that the involvement of the autistic community both in the creation of the materials as well as in their validation of the effectiveness of the tools provide the foundational evidence for supporting their use in practice. However, this qualitative evidence base can and should be further investigated using empirical methods.

Acknowledgments

We would like to express our sincerest gratitude to each of the following contributors who granted us permission to lend their voices to this clinical focus article and to share with readers: Michael John Carley, Patti Menzel, Jess, Autistic Typing, Dena Gassner, Jules Edwards, Stephen Shore, The Autistic OT, The Secret Life of Rose, Tee Monet writing as Unmasked, a neurodiverse mother and her 7-year-old neurodiverse son, Ama L., Kaylen Randall, Kristy Forbes of Kristy Forbes- InTune Pathways, Kieran Rose of the Autistic Advocate, Chris Bonnello of Autistic Not Weird, Chloe Rothschild, and Robyn Allison. Their willingness to share their insights, experiences, and wisdom will assist in our aim of furthering society's understanding, appreciation, and models of support.

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