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The Right to Belong, The Right to be Different

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VIGNETTE

Michael was honored to be invited to serve on the Consumer Advisory Board of the Office of Intellectual Disability within the County Department of Human Services. A 27-year-old man with Down syndrome, he had been a lifelong recipient of the agency's services. He appreciated the chance to give back. His social worker asked him what might make him successful in this important role. Together, they decided he would have a mentor attend the monthly meetings with him. One of his favorite high school teachers accepted his invitation to serve as his mentor.

Michael was inducted into the 20-person board with a physician, member of the clergy, social worker, and parent of a child with disabilities. At his first meeting, the director charged the board with revising the strategic plan. Michael sat at the corner of the square table; his mentor sat inconspicuously behind him, slightly back from the table. She periodically leaned in to check that he understood the discussion and to answer his whispered questions. When it came time to write strengths and weakness of various programs on sticky notes and place them on the appropriate easel pad sheet, Michael completed the task without assistance. His large, precise print and brief answers were easy for everyone to read. When discussion followed, Michael, with mentor encouragement, raised his hand and contributed pertinent comments. His speech was slow and intermittently dysfluent. However, over the course of the meeting, everyone at the table slowed their pace of speech. With the slower rhythm, they frequently acknowledged good points, asked for clarification when they did not understand, and let go of political maneuvering. They listened more and interrupted less. When the meeting concluded, the long-standing board members agreed it had been the best board meeting they had yet attended.

In this final chapter we, the editors, seek to summarize the content of this book within the framework of two of our overriding values and beliefs: the right to belong and the right to be different. We edited this edition of the text during the COVID-19 pandemic. It was a time of great political and social unrest, forcing us to confront vast inequities within the US population and across the globe—inequities based on race, ethnicity, income, ability, gender identity, sexuality, income, and country; inequities in health care access and quality, education, social service, income, environmental conditions, and public safety. In this changing social, economic, and political context it seemed particularly important to emphasize the values that undergird our collective work. We value diversity, equity, and inclusion to achieve justice and fairness.

We want to express our gratitude to the editors of previous editions of the text, pioneers in developmental-behavioral pediatrics, whose earlier editions of the book not only defined the parameters of the field but who also articulated these values. We want to acknowledge the many patients and families whom we have served as clinicians in developmental-behavioral pediatrics. They inspired the vignettes that launch each chapter. We came to realize that their stories humanize the content, making research studies specific and general points memorable. We find that their stories stimulate empathy and compassion. Like Michael in the opening vignette of this final chapter, they remind us that unexpected gifts may come with a commitment to diversity, equity, and inclusion.

THE RIGHT TO BELONG

Developmental-behavioral pediatrics involves evaluating and treating children, adolescents, and youth who have differences in relation to age-matched peers, either in terms of developmental skills, behavioral profile, physical appearance, family circumstances, psychosocial history, or (often) a combination of these features. These children may be diagnosed with neurodevelopmental conditions, such as attention-deficit/hyperactivity disorder (see Chapter 46), cerebral palsy (see Chapter 39), or genetic disorders (see Chapter 24). They may demonstrate variations in temperament (see Chapter 80), learning style (see Chapter 47), gender identity (see Chapter 75), or sexual orientation (see Chapter 74). Historically, many of these children were excluded from mainstream settings, such as general education and competitive employment (see Chapter 1). Still today, despite legal protections (see Chapters 112–114) and changing community norms, many children and adolescents, like those discussed in these chapters, and their families experience social isolation, ostracism, ridicule, and/or bullying.

Children with neurodevelopmental differences are more likely than other children to be economically disadvantaged or to come from minoritized groups. They face the harmful effects of social bias and institutional racism (see Chapter 20). They often experience elevated levels of social and physical stress (see Chapter 56). The construct of intersectionality captures the overlapping and interdependent systems of discrimination and disadvantage that affect these children and families.

We believe that the children discussed in the chapters of this text have the fundamental right to belong in our families, classrooms, neighborhoods, workplaces, and communities. Human society benefits from diversity. Our community is enriched through the full participation of individuals, like Michael in the opening vignette, with a wide range of life experience, skills, knowledge, and backgrounds. Diversity brings distinct and new perspectives to our social groups. It can encourage creativity, improve communication, and stimulate empathy. But more than any single advantage we could list, including children who represent the diversity of the human condition is simply the fair and just thing to do. It acknowledges that we share a common humanity.

There remains a great tension between societal appreciation for human diversity and the expectations that people will conform in appearance, ability, attitudes, and beliefs.

Impatience and intolerance are common responses to human variation. For example, adults often expect that children will learn to read with a single educational approach, without regard to their personal circumstances and history, distinctive temperaments (see Chapter 80), learning styles, and cognitive abilities (see Chapters 40 and 47). Before the pandemic, we educated children within large and often noisy classrooms, with limited individual attention and few accommodations. During the pandemic, we rapidly shifted to online, remote education. We expected all children to learn equally well in virtual classrooms. We did not consider how children would do without the benefit of multisensory approaches, close relationships with teachers and other adults, and easy access to friends. We continued to expect children to learn without any accommodations for the vast differences in their social situations, including the amount of food in the cupboard, the warmth of their homes, the relationships among their family members, and the ability of their parents or siblings to help them with homework. During the pandemic, we expected children to participate in online education without sufficient regard for the availability of adequate computer devices and the quality of their broadband wifi network (see Chapter 21). We often failed to develop strategies to make it possible for children to participate in and benefit from education, even as the circumstances of education shifted widely. In the spirit of equity we need to build an educational system that works for all children.

We also need to build a health care system that works for all people, including those with long-term or serious illness and disability. Medical care, especially for children with medical complexity (see Chapter 59), often fails to meet the children's needs. It is characterized by severe workforce shortages, poor coordination, high expense, and difficulties with access. Children are often underinsured or have public insurance that is not universally accepted (see Chapter 114). As a result, these children have multiple unmet needs, compromising their ability to belong.

Parents make accommodations for their children with neurodevelopmental differences. Many report that they cut back their work hours or quit their jobs to meet the needs of their children. This sacrifice may result in reduced family income. Parents often find themselves assuming the roles of service coordinator, advocate, nurse, teacher, therapist, and caregiver. Parents may need to cope with the emotional consequences of having a child who is different, including their own sense of sadness, isolation, fear, worry, and sometimes anger. These emotions may adversely affect the relationship between parents and their children (see Chapters 12 and 13) and parents and their medical clinicians and service providers. Other family members, particularly siblings (see Chapter 12) may also be impacted. We need to build systems to support children and families so that they belong, remain healthy, and participate fully in family and community life.

In the current era many countries have adopted legal protections that confirm the right to belong and offer protections against prejudice and isolation (see Chapter 112). The Universal Declaration of Human Rights, adopted on December 10, 1948, by the General Assembly of the United Nations, proclaims that "all human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood." The 30 articles of this document remain the standard for human rights and serve as the foundation for national legislation. In the United States (see Chapter 112), P.L. 101-336, commonly known as the Americans with Disabilities Act (ADA), prohibits discrimination against individuals with disabilities in the workplace and allows for accessibility in public transportation and in public accommodations (e.g., stores, restaurants, and public buildings). The legal foundation for a free and public education for all is the Individuals with Disabilities Education Act (IDEA) (see Chapter 113). It mandates a free and public education for all children with disabilities in the least restrictive environment.

Yet, the right to belong remains tenuous. Legal protections in the workplace and public accommodations, and the right to a free and public education in the least restrictive environment, remain subject to the political will of the nation. Threats to these laws arise regularly. Special education (see Chapter 104), for example, may be presented to the public as an unnecessary financial burden on a community rather than as a civil right. This attitude is particularly short sighted. Though approximately 10% to 20% of schoolchildren receive special education, these supports are far less costly than the outcomes of limited opportunity and neglect, including underemployment, incarceration, institutionalization, and the cycle of poverty. Nonetheless, public programs, including public education, remain underfunded.

We, the editors, recognize that to support equity and inclusion, we must confront our own assumptions and biases. Moreover, we must eliminate social and institutional barriers to belonging. We know that to achieve equity, some individuals and their families will need more resources, supports, and services than others will require. In addition to serving individuals, we commit to advocating for those supports and services as components of a just and fair society where children with differences and their families fully belong.

THE RIGHT TO BE DIFFERENT

Management and treatments in developmental-behavioral pediatrics are often designed to help children to function as well as possible in their family, school, or community. Many modalities of treatment are available, including counseling (see Chapter 91), behavior management (see Chapter 93), psychopharmacologic interventions (see Chapter 99), cognitive-behavioral therapy (see Chapter 98), occupational and physical therapy (see Chapter 106), speech-language pathology (see Chapter 107), and art and music therapy (see Chapter 108). A casual reading of this book might suggest that the professional clinicians in this field seek to normalize children to an implicit idealized version. We, the editors, want to reaffirm "the right to be different."

We believe that the focus of management and treatment in developmental-behavioral pediatrics is enhancing a child's functioning rather than correcting a difference. Clinicians must be humble, cautious, and self-reflective when we design management plans and treatments for children who are different. Advances in genetics, pharmacogenomics, medical and surgical interventions (see Chapter 23), and care of the complex child (see Chapter 59) have drastically changed the course of care for many children with developmental disabilities. Despite these improvements, including dramatically increasing life expectancy, health care does not cure many of the conditions we care for in developmental-behavioral pediatrics. We must remain aware that our well-meaning attempts to offer treatments may result from complex motivations and that many interventions bring potential adverse effects. We can often support an individual through simple means. In the opening vignette the keys to success for Michael were a mentor and a change in the expectations and behaviors of the rest of the board. We can model acceptance and respect as the foundation of any treatment plan.

The goal of enhancing function may encompass one or more domains of function, as described in the International Classification of Function, Disability, and Health (see Chapter 1), including learning and academic performance, mobility (see Chapter 106), communication (see Chapter 107), social relationships, work, and community life. Even then, however, it can be difficult to determine what is and is not an appropriate target of treatment. We should look to the families, and as soon as they can participate, to children or adolescents, to define for us what they most wish for to ensure the best quality of life.

Counseling (see Chapter 91) and individual psychotherapy (see Chapter 96) can raise significant ethical questions. To what extent is the therapeutic counseling designed primarily to edge the child toward uniformity and conformity? How do we ensure that therapists do not superimpose their own values on naive children? How much should parents and therapists press the development of social skills for a youngster who prefers to be alone? If a child has gross motor delays or is clumsy and shows little or no interest in sports, how important is physical therapy or adaptive physical education for the child? Even among children with minimal differences from the norm, when could they be allowed to determine their own academic and recreational direction?

Though we may provide management and treatments to improve a child's functioning, at the same time, children should be afforded the right to specialize. When families were large, it was not unusual for each child to assume a different adult role. We tolerated, even expected, this diversity. In an era of small family size we want our one or two children to successfully fill many different roles and expectations. Children may need help in resisting the overriding drive of adults to make them good at almost everything. At the very least, one should pause when a youngster about to undergo therapy protests, "You know, I like who I am." We must modulate our zeal to help children to function in a complex society and respect their individuality. We must balance encouraging exploration, excellence, and change with support and acceptance. We must contribute to making all children feel valued for who they are.

The inadequacies of service, fiscal, and social supports for families caring for children with severe disabilities in the home may prompt a great desire for change. The "right thing to do" may not be straightforward. The rights of children with disabilities must be balanced with the interests of the adults who take care of them (see Chapter 117). The use of psychoactive medications (see Chapter 99), for example, may quickly alleviate challenges in raising or educating a child with atypical behaviors; however, families need to weigh that option against a child-focused program of primary assistance in behavioral adaptation. Parents must try to come to a decision that balances the child's best medical interest and the family's needs and resources. The use of stimulant medications for children with inattention and hyperactivity (see Chapters 46) is also controversial. When is the use of stimulants correcting a neurobiologic condition and when is it enhancing performance? What should we do when a family rejects the option of using medication if the alternative is placement of that child in a restricted educational environment or repetition of the grade? Open dialogue among all parties, importantly including the child or adolescent and, if necessary, an impartial representative of the child, might help with such difficult decisions.

The tension between acceptance of difference and push for change can affect entire groups as well as individuals. These days, groups may resist the pull toward integration and normalization. For example, the Deaf community (see Chapter 42) appreciates the resources and protections it has received under ADA regarding telecommunications. Special communication devices such as teletypewriter machines (TYY) were mandated for individuals who are deaf or hard of hearing, making communication with others far easier than it had been. However, in the medical arena, cochlear implantation has become routinely available (see Chapter 42). This technology is akin to a prosthesis that can allow some degree of hearing in individuals with profound hearing impairment. Whether or not to have a child with congenital deafness get a cochlear implant has become a highly contentious issue. The

Deaf community, the capital letter here very important, does not conceptualize hearing impairment as a disability. Rather, it defines deafness as a community or culture, with its own language (American Sign Language), history, humor, values, and beliefs. Thus many individuals who are Deaf choose not to have cochlear implantation for themselves or their children. We can ask who should decide about the cochlear implant for a deaf child of Deaf parents?

Likewise, individuals with various forms of skeletal dysplasia have come together and formed a vibrant group known as the Little People of America. They advocate for accessibility in the workplace and in the community. They welcome modifications that allow them to drive and work within the community. However, they often choose to have children with other members of their group with short stature, a decision that often results in another generation with skeletal dysplasia who also require accommodations at home and in the workplace.

The neurodiversity movement has taken hold since the last edition of this textbook. On the one hand, the movement views individuals with autism (see Chapter 41) and other cognitive impairments, such as learning disabilities (see Chapter 47), simply as folks who fall within the wide range of normal human ability and behavior. The movement embraces the view that these conditions represent a complex combination of strengths and challenges. It encourages self-advocacy. It urges employers to recruit workers with autism and related conditions and to accommodate them in the workplace. At the same time, proponents want neurodiversity to be recognized as a disability within the context of employment so that individuals can enjoy the protections against discrimination and receive accommodations based on disability (see Chapter 112).

Similar issues arise regarding decisions about education placement. The least restrictive environment is usually interpreted to mean that children with learning disorders and other educational needs receive their education alongside typically developing children in a general educational environment (see Chapter 113). The effect of IDEA on children with developmental disabilities has been incalculable in terms of minimizing differences on many levels (see Chapter 1). Moreover, typically developing children who grow up with children with learning differences and disabilities alongside them in the classroom become more accepting of differences, and more able to see the “person” with a disability, rather than the disability itself compared to peers without this educational experience. However, some parents insist on placing their children in specialized classrooms or programs. They may worry that their children will not be adequately educated if they are a minority in the classroom. Others have seen their children ridiculed or bullied in those regular education settings. Yet others base their decisions on the actual schools and communities in relation to their child’s preferences and abilities. It challenges us when two of our fundamental beliefs—inclusion and personal choice—conflict with one another. How should we come to a decision about educational placement when the family and the professionals disagree? How can we arrive at consensus? How can we monitor the impact of our decisions to adjust, if necessary?

A FINAL WORD

In conclusion, the vast variations in human presentation delineated in this book can be considered the products of the array of phenotypic, genotypic, socioeconomic, cultural, political, and individual circumstances that characterize our species. The concept of normal or average is statistically perceivable but often subject to political inducement, and it is assuredly irrelevant on many occasions. We are heartened by changes in the values, attitudes, and beliefs of large swaths of the public to champion individuals’ right to belong and right to be different. We are grateful for changes in the practices of many clinicians who work with individuals with differences, providing care and support that facilitate participation and celebrate individuality. Yet, we have much to learn in this process. We must challenge ourselves to face our biases, uncover assumptions, open our hearts, and adjust our old ways. We must inspire our family members, coworkers, and friends to do the same. As members of developmental-behavioral pediatrics, we pledge to work to promote equality and acceptance even as we recognize and appreciate the value of individual differences. Please join us in a commitment to opening doors, making space, listening with compassion, serving, and welcoming all within our communities.