Understanding the Misunderstood in Emergency, Hospital and Outpatient Care for Special Populations

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By

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This book is dedicated to my heroic brother, Zac, who epitomizes on a daily basis the desire to excel and transcend some of the most significant challenges that nature can impose. Zac is brilliant, kind and handsome - you can peer into his eye on the front cover!

I would further like to dedicate this book to the misunderstood, and all those who seek to understand them.

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FOREWORD

On August 23, 2013, Ethan Saylor, a warmhearted young man with Down syndrome, went to the movies. Ethan never came back. Just a few years later, on Feb 4th, 2016, Kayden Clarke, a very bright individual with Asperger syndrome, was killed by police officers conducting a wellness check. Ethan and Kayden are just two of the countless souls who have experienced adverse outcomes in the midst of an acute behavioral crisis. These occurrences are all too common among individuals with one or more developmental disabilities.

Indeed, there has been a recent surge in press coverage, questioning the law enforcement community's approach and suggesting inadequate preparation for working with the special needs population. However, the problem of inexperience and lack of training does not stop there. Indeed, it also runs rampant among healthcare personnel.

Having worked in multiple emergency, hospital and primary care settings throughout the country, I have

sadly observed numerous occasions upon which medical professionals have difficulty in their interaction with individuals with neurodevelopmental disorders. I have witnessed misattribution of behavioral crises to intoxication, a frightened autistic patient sitting isolated in the middle of a bustling hospital hallway and medics speaking with patients using medical jargon that anyone would have difficulty processing, especially in a traumatizing emergency situation.

In order to more objectively characterize the problem, I conducted a study among my co-resident physicians. 60% reported little to no confidence in caring for a patient with a developmental disability. Similarly shocking, only half of respondents indicated that they felt confident in managing an acute behavioral crisis.

Unfortunately, a severely limited understanding of special needs continues to pose a serious hazard, in both the clinical and community settings. This lack of understanding not only significantly impairs the relationship between the provider and the individual, but has also rendered care more challenging and dangerous, in all contexts. From a healthcare provider's perspective, the ability to identify and more comprehensively understand individuals

with special needs is essential for safe, compassionate and comprehensive medical management. In the outpatient setting, this recognition can facilitate earlier referral to special education and recreational programming, as well as critical implementation of home and community-based waiver services and social security benefits. From a law enforcer's perspective, familiarity with the disorders is tantamount to the safe and ethical management of these persons in the criminal justice system.

As a result, I have developed an easily accessible and compact guidebook, incorporating key evidence-based considerations and strategies for working with this unique population. In my first section, I provide a background and lay out the medical disease associations and unique physical, emotional and mental characteristics, potentially influencing the care of individuals with Down syndrome, cerebral palsy and/or autism spectrum disorder. I then proceed to describe strategies specific to first responders, ambulatory/inpatient healthcare providers, as well as special needs individuals, their family and/or caregiver (s). This book is formatted such that it can be easily incorporated into a training curriculum as a textbook. It can also be stored in a

nursing station, the back of an ambulance, fire truck, emergency or police department. Further, one may choose to access it in digital form on a mobile phone, for quick reference purposes in an emergency situation.

My objectives for this literary piece are multifold. The primary aim is to deepen the understanding and strengthen the bond between the provider and the developmentally disabled individual, family and/or caregiver (s). Just as importantly, I strive to empower special needs individuals and providers, so that all can be prepared and equipped for both planned medical visits as well as unexpected clinical encounters.

PART I

BACKGROUND

The objectives for Part I are as follows:

- Define "developmental disability"
- Describe the importance of preparation for working with this unique population
- Characterize the psychological and physiological manifestations of each disorder

CHAPTER 1

WHAT IS A DEVELOPMENTAL DISABILITY?

A developmental disability is a serious lifelong disability, affecting cognition, physical function or both. According to the American Association of Intellectual and Developmental Disabilities, the criteria for an intellectual disability include the following:

- Limitations in intellectual functioning
- Limitations in **adaptive behavior (conceptual, social and/or practical skills)**
- Onset, although perhaps not recognition, before 18 years of age

SIGNIFICANCE

Developmental disability continues to become increasingly more prevalent within our population (Figure 1-1). In 2018, 1 in 59 American children were diagnosed with autism spectrum disorder (ASD), with annual costs

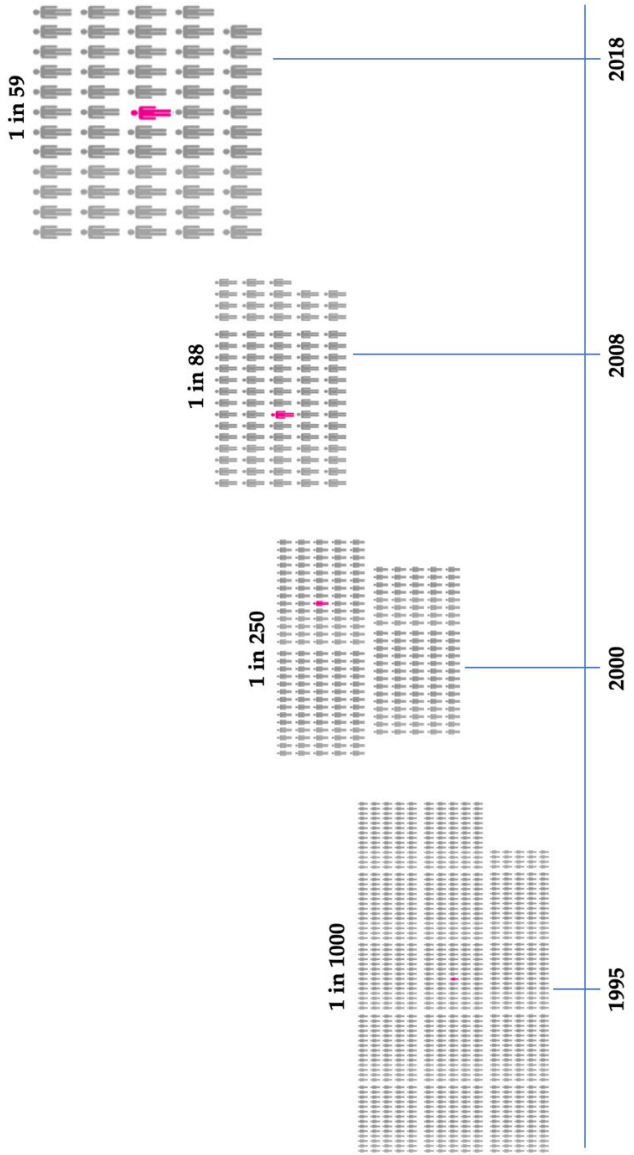

Fig. 1-1 The history of the prevalence of autism in the United States.

exceeding $268 billion, as of 2015[1]. In the absence of more effective support and interventions, these costs are projected to increase to $461 billion per year by 2025.

The situation is similar internationally. According to a Swedish study[2], these lifetime costs can be reduced by 2/3 with early intervention.

But the benefits do not stop there. Diagnosing and being aware of the wide-ranging implications of intellectual disability is crucial for innumerable reasons. From a healthcare provider's perspective, the ability to identify and more comprehensively understand individuals with special needs is essential for safe, compassionate and comprehensive medical management. In the outpatient setting, this recognition can facilitate earlier referral to special education and recreational programming. In addition, the critical implementation of home and community-based waiver services and social security benefits can be introduced.

As can also be demonstrated, familiarity with the spectrum of neurocognitive disorders is tantamount to the ethical treatment of individuals with developmental disabilities in the criminal justice system.

CURRENT SITUATION

Yes, we recognize that the prevalence of special needs is increasing throughout our population… but are healthcare professionals prepared? Where do we as medical personnel stand in terms of our training and experience with working with these unique individuals? Well, I have already described the various transgressions I have personally observed, at clinical settings throughout this country. Special needs-focused training is also, quite surprisingly, not a mandated aspect of the medical education curriculum.

However, in order to acquire a more objective idea of the current state of affairs, I conducted a study at my own internal medicine residency training program. My survey anonymously evaluated patients with a developmental disability (DD), including the following:

- Recognition of a DD
- History and Physical Acquisition
- Medication reconciliation
- Acute behavioral crisis management
- Social assessment, advocacy and intervention

The survey results are detailed in the charts below. Note that regions highlighted in red reflect minimal to no confidence or experience.

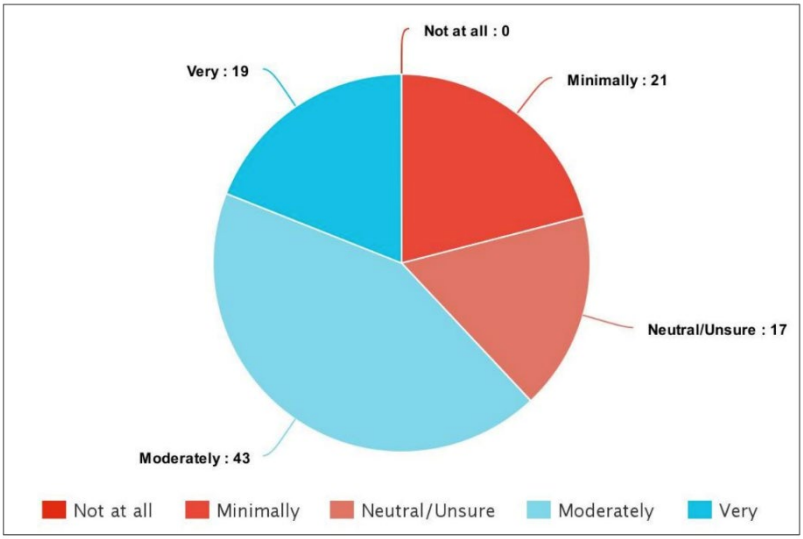

Fig. 1-2 The degree of provider confidence in recognizing a DD.

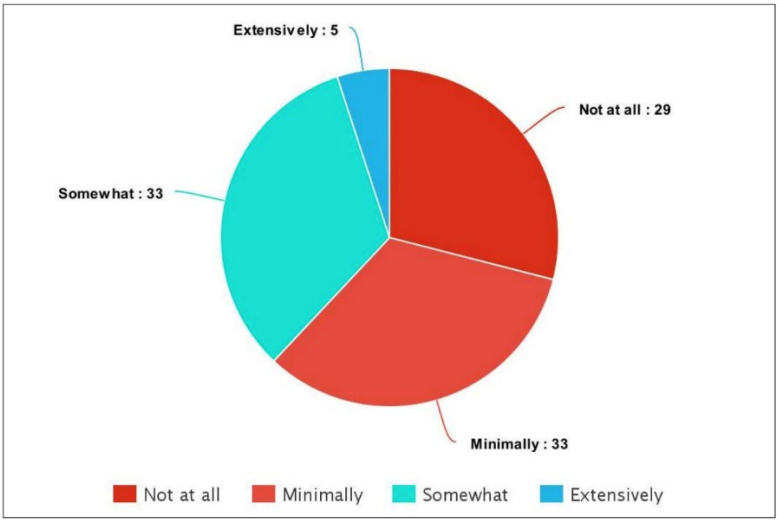

Fig. 1-3 The extent of prior preparation of the provider for working with the special needs population.

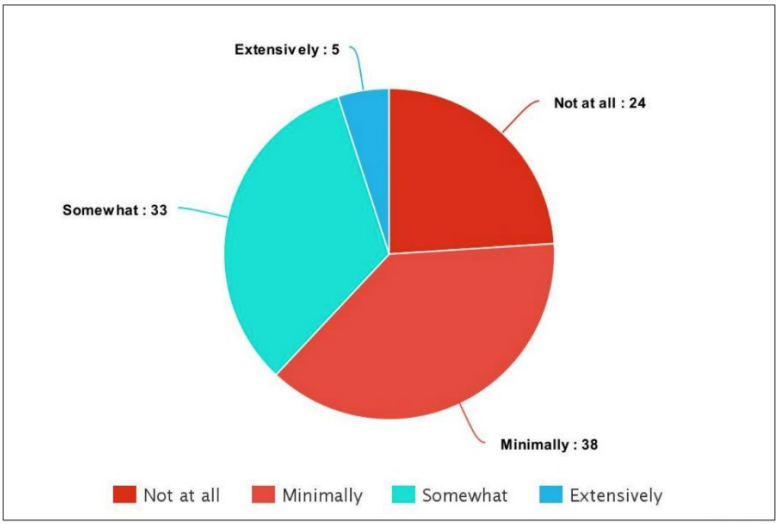

Fig. 1-4 The extent of provider education about unique features of each DD.

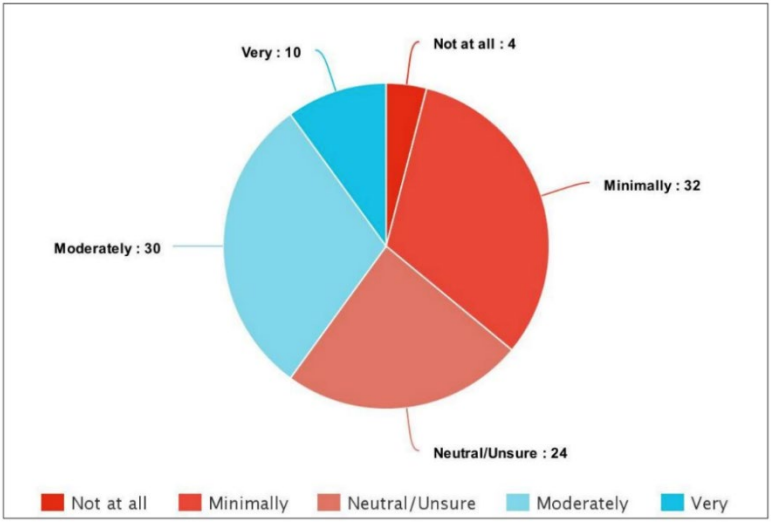

Fig. 1-5 The degree of provider confidence in overall care of a patient with a DD.

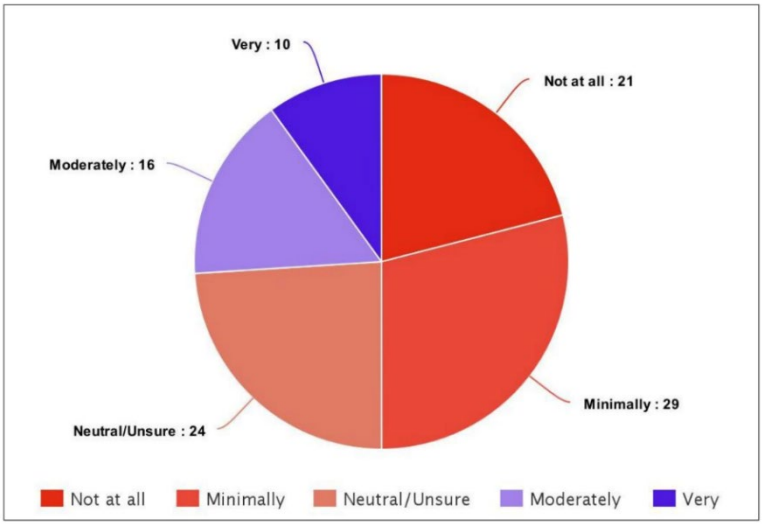

Fig. 1-6 The degree of provider confidence in acquiring a history and performing a physical exam on a patient with a DD.

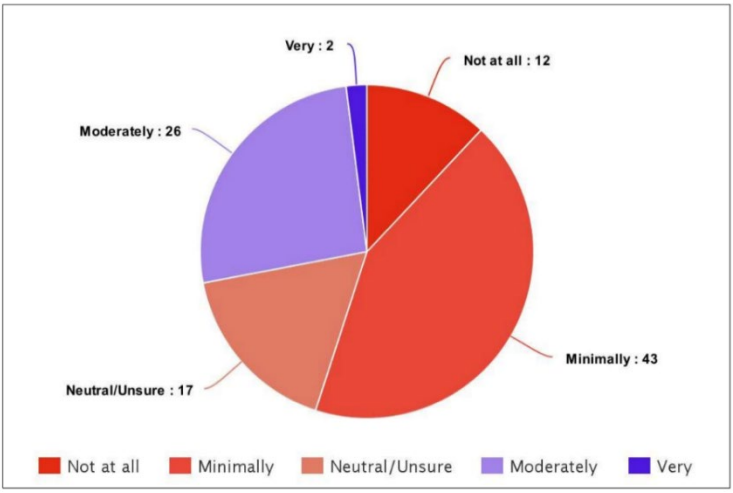

Fig. 1-7 The degree of provider confidence in managing a complex medication regimen for a DD patient.

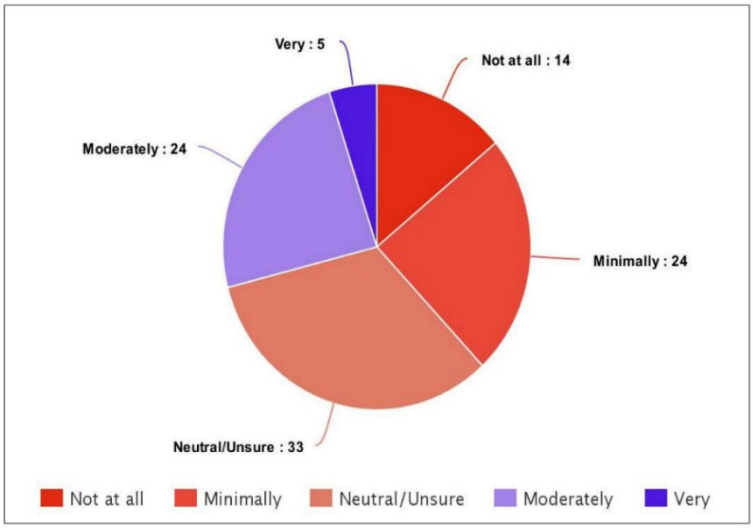

Fig. 1-8 The degree of provider confidence in managing social issues pertaining to a DD patient.

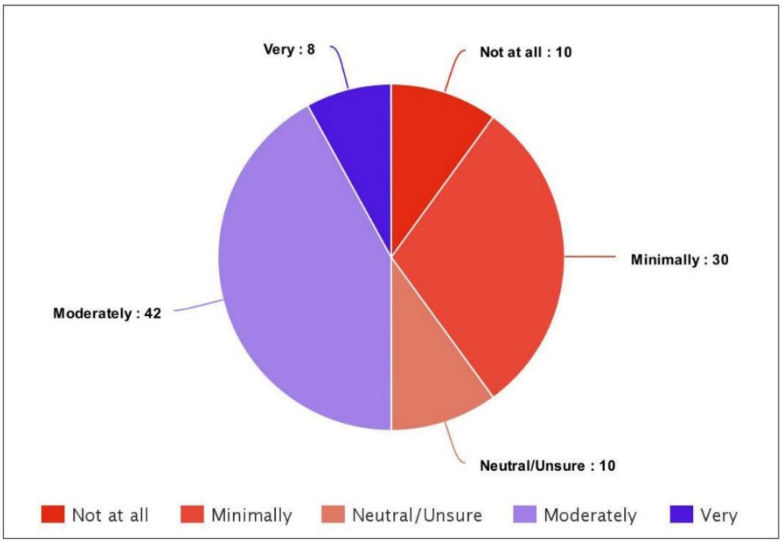

Fig. 1-9 The degree of provider confidence in managing an acute behavioral crisis.

Note just how much red there is! 62% of trainees felt strongly confident that they could identify a patient with a developmental disability (Figure 1-2). However, 62% also reported feeling minimally prepared to work with special needs folk and have had little to no prior education about the unique physical considerations involved in their care (Figures 1-3 and 1-4). Along similar lines, 60% have cared for a person having a developmental disability at some point in their training or career thus far, but the same proportion had little to no confidence in doing so (Figure 1-5). Over 70% of residents

had little to no confidence in acquiring a history and performing a physical exam, managing medications and addressing social matters pertaining to these unique patients (Figures 1-6, 1-7 and 1-8). Only 50% of respondents were relatively confident in their ability to manage a patient with a developmental disability in an acute behavioral crisis situation (Figure 1-9).

Based on these results alone, an educational intervention and further preparation is highly warranted.

CHAPTER 2

AUTISM SPECTRUM DISORDER (ASD)

ASD is defined as a heterogeneous group of complex disorders of brain development, characterized, in varying degrees, by difficulties in social interaction and verbal and nonverbal communication, and repetitive behaviors. While individuals may certainly adapt and improve over time, ASD is generally considered a lifelong developmental disability.

Given the wide variation in attributes and capacity within this population, ASD is truly represented by a spectrum. In fact, based on vastly diverse patterns of functioning and personality, it may be very difficult to even identify that a certain individual actually has autism!

In spite of their challenges, many individuals with ASD throughout history have an astounding record of achievement and have contributed greatly to society. Musician Wolfgang Amadeus Mozart, activist Temple

Grandin and singer Susan Boyle are just some of the many legendary individuals on the spectrum.

Signs of autism can be subtle. The diagram below documents some of the most important clues (Figure 2-1). However, note the spectrum represented. Not every autistic individual will exhibit all signs, and the degree to which each sign is present can be highly variable.

There are also some objective tools that can be used in the clinical setting, in order to evaluate whether someone could be on the spectrum. A provider can administer the well-validated Autism Quotient-10 (AQ-10) scoring system (Figure 2-2)[3], if he or she has suspicion that a patient may be autistic. However, note that one must ascertain a patient's language preference, ability to read and write and the presence of any learning disability that could lead to an inaccurate assessment by such a form. Furthermore, while a positive quotient result may help support one's suspicion of ASD, it is not diagnostic. Indeed, the AQ-10 score is not a substitute for more definitive neuropsychological testing, which should be performed by a specialist.

Fig. 2-1 The wide variation of signs of and patterns of behavior in ASD.

Please tick one option per question only:		Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1	I often notice small sounds when others do not				
2	I usually concentrate more on the whole picture, rather than the small details				
3	I find it easy to do more than one thing at once				
4	If there is an interruption, I can switch back to what I was doing very quickly				
5	I find it easy to 'read between the lines' when someone is talking to me				
6	I know how to tell if someone listening to me is getting bored				
7	When I'm reading a story I find it difficult to work out the characters' intentions				
8	I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)				
9	I find it easy to work out what someone is thinking or feeling just by looking at their face				
10	I find it difficult to work out people's intentions				

SCORING: Only 1 point can be scored for each question. *Score 1 point for Definitely or Slightly Agree on each of items 1, 7, 8, and 10. Score 1 point for Definitely or Slightly Disagree on each of items 2, 3, 4, 5, 6, and 9.* If the individual scores **more than 6 out of 10**, consider referring them for a specialist diagnostic assessment.

Fig. 2-2 The AQ-10 quotient. [3]

ASD can occur alone, or be associated with or mimicked by the following conditions:

- Congenital Rubella
- Cornelia DeLange
- Fragile X syndrome
- Kluver-Bucy syndrome
- Rett syndrome