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# Life on the Autism Spectrum

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# Preface

In 1980, autism was included for the first time as a distinct diagnosis in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-III).* This sparked a flurry of speculation, media attention and research, which has only increased in the ensuing decades as more people have attempted to understand the phenomenon of autism. Along with the growing public awareness of autism has come an increasing number of myths and misconceptions about the condition as well as of autistic people. Not only has this created a plethora of inaccurate conceptions about what it means to be "autistic", but many of these myths are centred on the perceived deficits and limitations of autism and autistic individuals. More importantly, it could be argued that this has created a "culture of apprehension and fear" of autism and, by association, of autistic people. Certainly, it has created a public perception that people on the autism spectrum are limited by their autism and are not capable of achieving the same outcomes as their non-autistic peers.

The initial impetus for this book was a desire to analyse and debunk the foremost myths about autism. Upon closer examination, however, we quickly realised that this would involve much more than just presenting the current research and facts. If we wished to truly change the public's attitudes and assumptions about autism, we had to unpack the factors that have created these myths as well as look at the continuing deficit-based beliefs that underlie and maintain them. We would also need to create an alternative perspective of autism and autistic individuals, viewing them not as "disabled" but as unique and capable individuals whose primary need is a support to navigate the complex expectations of their environments and to manage their own innate challenges and anxieties. In this book, we have attempted to create a discourse regarding the myths and mythologies of autism in order to discover the current ways in which these myths are promoting a deficit-based model of autism and negatively impacting and limiting autistic individuals. While we acknowledge that there are a number of autistic individuals who experience ongoing challenges that have a significant impact on their lives, we believe that a dialogue based solely on these individuals' "disabilities" is counterproductive to creating the environments and supports required to enable them to build their knowledge, skills and competencies as adults. Rather, it is our intention to offer an alternative perspective whereby all autistic individuals are viewed as possessing individual strengths and potential competence if they are provided with the opportunities to build on their unique ways of thinking, working and engaging with the world around them. It is our contention that this involves not just enabling autistic individuals to develop the skills needed to engage more effectively with a non-autistic world, it also means that the non-autistic community needs to spend the time and effort to learn the perspectives of autistic individuals so that they can also adjust their ways of working. More than anything, this will necessitate new ways of interaction in which autistic individuals and their non-autistic counterparts listen to each other in order to modify their own personal styles and create new and more effective means of communicating with each other.

This point was illustrated to us as we began to work as a group to complete this text. As a group of autistic and non-autistic individuals, we discovered that to effectively work together, we needed to explore our assumptions both about ourselves and about each other in order to actively listen to each other and recognise that each of us had our own unique ways of looking at the world, and that we could not presume the intentions of the others. To work together, we needed to be open to expressing our individual needs and working through how we could accommodate the needs of each other. We also recognised that we each brought individual skill sets, which although different, added additional elements to provide a comprehensive understanding of the phenomenon of autism. Thus, by working together to write this book, we also developed key learnings we wished to convey through the book.

This book begins, in the first chapter, by exploring the reasons that myths develop and autism myths have become so prevalent in our society. In the subsequent chapters, eleven myths are presented. In each chapter, the origins of each myth are explored, followed by a presentation of the current research and facts relevant to the myth. This is followed by an analysis of the ways in which the myth is continuing to impact autistic individuals. In the final section, we provide an alternative view of the myth and suggest the means required to create a more positive future that empowers autistic individuals rather than focuses on remediating their perceived deficits. Throughout this book, we have utilised identity-first language to reflect the current preference of the autistic community, and to convey a message of empowerment in supporting autistic individuals to claim their identity, rather than be limited by the labels placed on them by others.

In today's society, increasing tensions have developed between the various groups of people involved in the lives of autistic individuals. These include parents and family members, service providers and professionals, researchers, policymakers and, of course, autistic individuals. It is our hope that through this book, we can stimulate a valuable discussion which can bring these people together so that they can identify their shared goals and create more effective ways of collaboratively working to create opportunities and supports to achieve these goals. Most importantly, we hope that this book offers both a paradigm shift in thinking about the autism spectrum as well as a vision for an alternative and positive future, which supports the competence of all autistic individuals, as well as a pathway for creating that future.

Wollongong, Australia

Amanda A. Webster
On behalf of the authors

# Acknowledgements

A book like this takes more than just the effort of the authors. It reflects the experiences and encouragement of a number of people. We would like to acknowledge our families and friends for the tremendous emotional support and understanding they provided as we worked to put this book together. We want to thank them for all the times they listened when the stress threatened to overtake us, and for putting up with all the late nights and weekends we had to spend at our computers.

We would acknowledge the efforts of Katrina Williams who agreed to edit our work and exercised real patience as we rushed to work through very short time frames. We would also like to extend a special thanks to India Webster for bringing our words to life with her wonderful illustrations.

Finally, this book would not be possible without the years of efforts of the many autistic individuals and families who have continued to raise their voice to challenge the prevalent perceptions and expectations of others. It is our wish that this book serves to change these perceptions and give strength to your voice.

# Contents

# Chapter 1

# Translating Autism Myths into Positive Futures

**Abstract** Since *Early Infantile Autism* was first described by Leo Kanner in 1943, myths and misperceptions about the nature of what is now known as autism spectrum disorder (ASD) have proliferated. These myths have played a role in shaping autism research and clinical practice and have impacted the way in which autistic individuals are viewed by others in society. This book will explore popular myths, beliefs and misconceptions about ASD and autistic people. Each chapter explores a different myth and begins by investigating the origins of the myth. The current research and impacts related to each myth will be examined and the underlying themes relevant to the lives of autistic children and adults will be discussed. At the end of each chapter, the authors will discuss the ways in which the myth can be reconstructed, in the light of current knowledge and research, and will provide recommendations for current and future practice. This book will start by reconstructing myths that relate to the ways that autism has been viewed by society. Next, the myths that reflect the public's perception of autistic individuals will be critiqued. Finally, this book will examine myths about the traits and abilities of autistic children and adults and will present an alternative view in which contexts are created and autistic individuals are presumed to be competent and capable of constructing their own futures.

**Keywords** Autism · Misconceptions · Myths · Pseudoscience

Myths often develop and are used by society to explain less tangible aspects of the world around them (Massey, 2002). Often what starts as an explanation of a tangible phenomenon develops over time to become a persistent and pervasive belief that no longer has any basis in reality. Although some may dismiss the enduring influence that myths and misperceptions can have on people's perceptions and beliefs, many current societal myths have significantly overshadowed scientific findings and resulted in individual actions that defy common sense. For example, the myth that "*you can't*

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The use of identity-first language is the preference of many individuals in the autism community (see Kenny et al., 2016). As the voice of the autistic community is integral to the focus of this book, the use of identity-first terms such as autistic individuals, autistic children, and autistic advocates will be used throughout this book.

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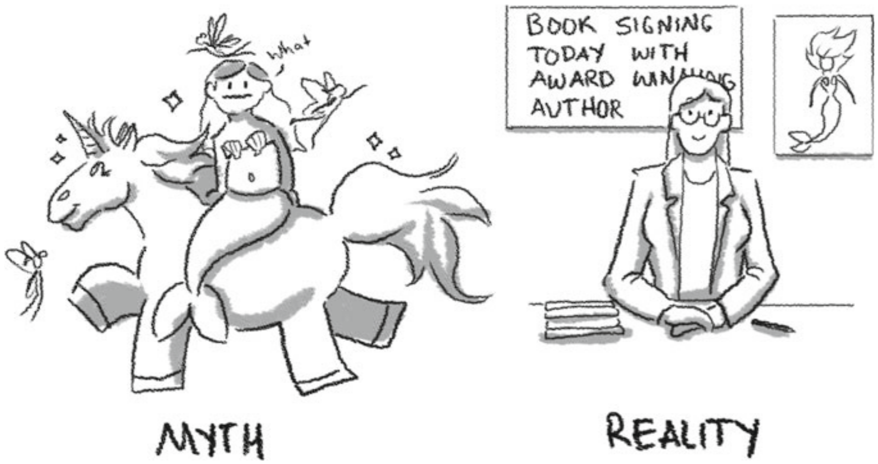
*get pregnant if you are breastfeeding*” is generally accepted as untrue. However, some young women still cite it as a reason for not using birth control.



Autism is associated with a number of the most persistently sustained myths. These myths have had a significant impact on the lives of autistic individuals and their families as well as on the way that society views and supports them. To be able to understand and negate the impact of these myths, it is important to first look at the nature of myths and how they develop.

## 1.1 What Are Myths and How Do They Develop?

The *Oxford English* Dictionary defines a myth as a widely held, but false belief or idea. Myths are stories or customs that inform and give meaning to a person, community or culture and are important to help people make sense of their lives (Morris, 1997). However, myths need to be examined to determine if they are having a positive or negative impact on individuals or society, and if negative, how and whether they can be altered.

One of the areas that is most susceptible to myths and misperceptions is the field of psychology. Myths in this area are so common that researchers (Lilienfeld et al., 2009) have coined the term *psychomythology* to describe the misconceptions and urban legends that have permeated the public’s understanding of many psychological constructs. In their examination of common psychological myths, Lilienfeld et al. (2009) liken many popular psychological myths to cognitive illusions, which fool the mind rather than the eyes. They argue that these myths become widespread because they align with the first impression or intuition of an individual or group. Mocarski (2014) adds that “myths are stories that speak of meaning and purpose and speak truth to those who take it seriously” (p. 2), while personal, family and cultural mythologies provide a foundation for more deeply embedded beliefs and myths. Mocarski also suggests that the study of myths is really the study of the communities' beliefs and values and the ways that they are passed from one person to the next. Furthermore, myths are not fixed, but are constantly evolving and changing, as society tries to assimilate and reconcile new information with intrinsically held beliefs. It can be argued that all myths contain both elements of truth and misinformation (Csiernik, Forchuk, Speechley, & Ward-Griffin, 2007). It is this combination of fact and misinformation that can have the most negative consequences for individuals.

In many ways, myths are theories that have taken on the illusion of fact in the collective consciousness, without being proven. They are an attempt to provide an explanation for a phenomenon that is observed repeatedly (Hayden, 2014). Myths develop over time and in a variety of ways. Many come from personal experiences, or from stories and beliefs related to culture or religion (Mocarski, 2014). At the foundation of many myths is fear. Many cultures have oral or written stories, or myths, that represent an attempt to explain unusual phenomenon that when not understood, made people afraid. Creating a myth that provides an explanation for the phenomenon can enable people to decrease their fear of the phenomenon.

Myths, particularly those related to health or psychology, often result from the gap between scientific inquiry, which is often highly specialised and difficult to access, and the public's need to make sense of an unexplained but problematic issue. For example, Mocarski (2014) argues that the myth that vaccinations cause autism has grown because there is a gap between the public's understanding and researchers' knowledge about the causes of autism. This example also highlights the intractability of many commonly held myths. Once they become enmeshed in the belief system of a group of individuals, challenging these myths becomes even more difficult, even when scientific research proves the myth has no basis in fact. Complexity of scientific theory can present additional challenges in refuting myths. As scientists have offered complex theories rather than simple explanations about the cause(s) of autism, concerned parents and professionals have often resorted to drawing their own conclusions.

The vaccine-autism myth also meets Mocarski's (2014) criteria of stickiness, which he defines as the lasting appeal that a myth has. To be long-lasting, a myth must have stickiness at all levels, including its origin, the ways it is enacted and the way it is remembered. The vaccine-autism myth has all of these. Pseudoscientists and the media have continued to produce stories that add to the seeming validity of the claim that vaccines are dangerous and may cause autism. Some health practitioners and anti-vaccine groups continue to support parents' refusal of vaccines for their children and continue to discredit scientific claims that vaccines are safe. Because this is such an emotional issue for parents, and autism is often characterised as a condition with harmful consequences, some parents have chosen not to vaccinate their children, deciding that the risk of their child contracting a vaccine-preventable disease is preferable to them developing autism.

Lilienfeld et al. (2009) identify errors in thinking that have led to the development of common psychological myths. These errors in thinking not only create misperceptions and myths, but help to sustain them by spreading them widely. By communicating these myths to more people who view them as plausible, they become so widespread that they become perceived as fact. In other words, they must be true, because everyone knows them and believes them to be so. Each of Lilienfeld et al.'s errors in thinking are commonly found in society and can be used to unpack many of the most widely believed myths.

Lilienfeld et al.'s (2009) first error in thinking is *word of mouth*. This is a particularly effective source of spreading a myth across a community or society. Verbal communication can convey simple, appealing and easily remembered, but fictional statements, which sound true but which are actually false. Word of mouth often relies on short, catchy phrases, which people readily remember. For example, the phrase *"an apple a day keeps the doctor away"* uses rhyme and rhythm to convey the myth that eating an apple every day will make you healthy. Of course, this is a gross oversimplification of the fact. Apples, while a healthy food, do not necessarily keep you healthy. However, the phrase is appealing and easy to remember, so people retain it and start to believe it. More importantly, when they repeat this myth to others, even if they do not believe it consciously, they are conveying their support for this myth. Although none of the myths about autism can be distilled into short, catchy phrases, word of mouth has certainly played a role in their rapid dissemination. One myth that is particularly easy to remember is the myth that autism can be cured. This myth also has the allure of offering a seemingly desirable outcome, which relates to another error of thinking.

A *desire for easy answers and quick fixes* (Lilienfeld et al., 2009), another error of thinking, is particularly likely in situations where individuals encounter problems that are complex and difficult to solve. This creates a tension for people who are motivated to believe that something can easily fix their problem as well as helping to perpetuate their belief that a solution works because they desperately need it to work. For example, for many people who either want or need to lose weight, the idea of exercise and eating healthily on a long-term basis is a daunting and not particularly pleasant prospect. As a result, they may choose instead to believe claims that taking supplements or going on fad diets will help them to lose weight quickly and effortlessly. Of course, this is not a long-term solution and often creates further problems as they may eliminate essential nutrients from their diet. Even if they later recognise that the diet did not work, they may be just as susceptible to the next claim of a miracle cure if it is still viewed as the more palatable option. It is the emotional investment and willingness to believe that create and sustain these types of myths. A similar idea is the belief of many people that special diets such as a gluten–casein-free diet can help to treat or even cure autism. Despite any lack of evidence for its effectiveness (Whitehouse, 2013), the relative simplicity of this approach has made it attractive to many parents.

*Selective perception and memory* is a third source of myths described by Lilienfeld et al. (2009). This error of thinking is linked to the brain's ability to selectively filter or focus on specific aspects of the environment if they relate to other things the person is already thinking about. For instance, when an individual meets someone who has a unique car, they start to remember other times when they have seen this type of car, or they might notice similar cars throughout the day. Likewise, once an individual has heard a claim or myth that relates to something in their life, they start to see evidence that appears to support the myth. For example, once an individual has heard a claim that a particular herb or oil will "treat" autism, they might perceive many ways in which the autistic individual has improved after they have been "treated". Unfortunately, while the individual is becoming aware of supporting examples, their brain is also filtering out other information which does not support the myth. In the example above, the parent or professional may be so focused on seeing improvement, that they may unconsciously dismiss evidence that shows the treatment is not effective. Since the brain is focused on seeing a certain detail, it tends to be more alert to its occurrence. It is this selective memory that supports the placebo effect that is sometimes noticed when people believe something is working.

Lilienfeld et al.'s (2009) next two errors of thinking are related to a tendency to see a relationship between two factors, which does not exist. The first of these, *inferring causation from correlation,* occurs when individuals assume that because two things are related, one must cause the other. The second, *post hoc, ergo propter hoc reasoning* relates to the belief that just because one thing occurs before another, it must cause that event or action. Both of these are common to psychological and health-related myths, but fail to consider the relevance of additional factors, which may actually be the cause of both the first and second elements. For example, many people have speculated that gut bacteria causes autism or autistic symptomology due to the fact that a person reports having pain before they exhibit other behaviours such as non-compliance or tantrums. It is possible, however, that sensory sensitivity to certain foods may result in poor nutrition and eventual gut problems. Alternatively, anxiety associated with autism may contribute to gut problems rather than vice versa. In addition, a new field of research (Mulle, Sharp, & Cubells, 2013) is investigating whether genetic differences that may cause autism also cause gut problems. In other words, both autism and gut problems could be attributed to a third physiological factor such as genetic anomalies.

The next error of thinking leading to myths is *exposure to a biased sample* (Lilienfeld et al., 2009). This happens when people make generalisations and judgments about a wider group of people based on their experience with a specific group. Basically, people form conclusions based on their subjective perception rather than the evidence. For example, a teacher who works with students with intellectual disabilities in an inner-city school where many students come from homes that are impacted by violence and drugs might conclude that most individuals with intellectual disabilities come from violent and drug-addicted parents. Of course, this is patently untrue and illustrates the natural human tendency to overgeneralise from personal experience. In another example, a person who has met a group of non-verbal autistic children may assume that all autistics cannot talk. This is why scientific inquiry and collection of objective evidence are so important.

*Reasoning by representation* is another source of myths in which individuals demonstrate a tendency to see relationships that do not exist (Lilienfeld et al., 2009). This error in thinking occurs when people assume that two things, which appear similar, are connected. For instance, a person may meet someone from a specific location and assume that this individual has a connection to another person from the same location. Another example is assuming that all people diagnosed with autism spectrum disorder will display similar behaviours or needs.

In today's society, *misleading film and media portrayals* have played a significant role in shaping people's beliefs, including creating false beliefs that eventually become myths (Lilienfeld et al., 2009). To get ratings, the media may dramatise phenomena in an effort to create a story or to make mundane facts more interesting and appealing to their audience (Beins, 2008). For instance, it is much more interesting to present stories about individuals with autism who have savant skills such as Raymond Babbitt from the movie *Rain Man* than it is to portray the average autistic person who does not have these skills. This overrepresentation of individuals with savant abilities has contributed to the myth that autism is synonymous with savant syndrome. Another of Lilienfeld et al.'s errors of thinking, *exaggeration of a kernel of truth,* is similar as it involves an exaggeration of claims that are based, at least in part, on fact. Since they have some basis in truth, these errors in thinking may be perceived as having a particular claim to legitimacy. An example of this is the common myth that autism is synonymous with behaviour disorders. Although it is true that some individuals, particularly children, diagnosed with autism spectrum disorder do exhibit challenging behaviours, these behaviours can be the product of a variety of individual and/or environmental factors. Certainly, it would be a gross exaggeration to suggest that all autistic children have behaviour disorders.

The last error of thinking is particularly common in scientific fields, such as psychology and social sciences. *Terminological confusion* results when people make the wrong assumptions about scientific or medical terms and vocabulary (Lilienfeld et al., 2009). Terminological confusion may arise from an incomplete understanding of specific terms or from the changing meanings given to terms over time. For example, the terms aural and oral are often confused as they are homonyms, and both relate to communication. Aural relates to the ear and the sense of hearing, whereas oral is linked to the operations of the mouth. In another example, the term dichotomy is often misused as a reference to a difference between two things when it actually means two mutually exclusive alternatives, like black or white. The term autism has undergone several changes since it was first used in 1911 (Greydanus & Toledo-Pereyra, 2012). Originally used to denote a form of schizophrenia, research over the past 30 years has significantly advanced the understanding of autism as a distinct neurodevelopmental condition. Despite this, there are still many who question the overlap between these two conditions (Fitzgerald, 2013).

The errors of thinking identified by Lilienfeld et al. (2009) provide a starting point for understanding many of the notable myths about child development and psychology. A number of these have become indistinguishable from fact in the public perception. In their book, *Great Myths of Child Development,* Hupp and Jewell (2015) describe a set of criteria for what they call the "great myths". These are myths that have taken hold in the public consciousness, are held as fact by a large number of people and have had a wide-reaching impact. Hupp and Jewell's criteria include:

- A lot of people have heard the myth;
- A lot of people currently believe the myth;
- The myth sounds true and is believable;

- The myth is supported by some professionals (or pseudoscientists);
- There is a great deal of scientific evidence to contradict the myth;
- People's belief in the myth can cause harm; and
- The myth discourages the use of another scientifically supported practice.

Hupp and Jewell (2015) and Lilienfeld et al. (2009) have explored some of the most widely held myths in the fields of psychology and child development. These include common myths such as *"you can learn languages in your sleep"*, *"handwriting reveals personality traits"* and *"dolphin therapy helps children with disabilities"*. All of these myths carry a degree of credibility with at least some individuals, but are not supported by evidence. All meet Hupp and Jewell's criteria for great myths. As one of these criteria is that myths cause harm, it is important that great myths be examined to ascertain their origins, to understand how to change the public's perception into a more accurate and scientific view, and to prevent further harm from occurring.

## 1.2 Myths About Autism

Autism is a field, which has been particularly susceptible to myths. Both Lilienfeld et al. (2009) and Hupp and Jewell (2015) include myths about autism in their discussion of great myths. Given autism's complicated history, and the diverse spectrum of characteristics and behaviours exhibited by autistic individuals, it is not surprising that a number of myths have developed in this area (Mocarski, 2014). Many of these can be linked to Lilienfeld et al.'s errors in thinking. For instance, assuming the relationship between autism symptomology and an external factor means that this factor must in some way cause autism is an example of *inferring causation from correlation*.

The media has also played a significant role in the spread of autism myths by presenting speculations about autistic individuals and airing debates about the causes and treatments for autism, without providing research or scientific evidence to support these stories. Some myths, such as the belief that vaccines cause autism, have been particularly sensationalised in the media, which is further compounded by statements of support from a number of celebrities such as Jenny McCarthy and Robert Kennedy Jr. (Offit, 2008). Vyse (2005) argues that celebrities possess a significant amount of power and can influence the public's attitudes and beliefs. When they promote misperceptions about autism, they help to build the public's perception that these beliefs have credibility (Nyhan, 2016).

Although autism myths have developed in different ways, the need for explanations and solutions to pressing problems, particularly from parents seeking answers and information to help their children, lies at the core of most myths about autism. Since autism was first identified in the 1940s, scientists and researchers have worked to gain an understanding of the nature of autism and the common characteristics demonstrated by autistic individuals. Unfortunately, much of the knowledge and research generated is not easily accessible to the public or has been very slowly disseminated (Pellicano & Stears, 2011).

More importantly, scientific research is often written in complex and difficult terminology, containing statistics and findings that are not easily interpreted by lay people who are not researchers or scientists. As Mocarski (2014) explains, the gap between scientific knowledge and public knowledge creates a climate for myths to develop. It could be argued that this is especially true in situations where people are dealing with highly emotional and stressful situations, and in which they face challenges for which they feel they have few answers or support. This is the case for a number of parents and professionals working with autistic children.

Two other reasons that myths about autism have become so widespread are the proliferation of popular psychology (Lilienfeld, Lynn, Ruscio, & Beyerstein, 2011) and a distrust of research and scientific inquiry (Camargo & Grant, 2015). In the twenty-first century, lay psychology has become common. This is evidenced by the number of self-help books and other types of sources promoting solutions for a variety of issues experienced by families and autistic individuals, such as dealing with anxiety and stress, curing children and eliminating challenging behaviours. It could be argued that the increased proliferation of self-help material has at least partly resulted from an increased public awareness of the link between mental health and emotional well-being and physiological health and positive outcomes and success.

This awareness has helped generate an increase in funding for psychological issues, which may have also contributed to the number of people offering services and treatments, many of whom may not have adequate training in scientific inquiry or evidence-based practices. This is evident in the number of individuals who have begun offering applied behaviour analysis (ABA) services and therapy as the market and money available for these services has increased. Keenan, Dillenburger, Moderato, and Rottgers (2010) contend that this has damaged the public's perception of the benefits of ABA, as practitioners who may be primarily interested in monetary gain have employed poor strategies under the guise of ABA. Unfortunately, these individuals and other popular psychology sources are readily available via the Internet and other media. Although these sources can provide high-quality information about human behaviour or topics such as autism, they often contain an equal, if not greater amount, of misinformation. Lilienfeld et al. (2009) term this body of misinformation *psychomythology* because it perpetuates myths and misunderstandings about topics related to the field of psychology.

Pseudoscience involves the use of scientific-sounding terminology and statistics to persuade people that an approach is backed by science. Unlike real science, which may take years or decades to research a hypothesis or practice, pseudoscience often offers quick and easy cures, meeting people's need for a rapid solution. As mentioned earlier, people tend to believe information they believe is likely to be true (Schwarz, Sanna, Skurnik, & Yoon, 2007) or that appeals to, or fits with, their beliefs and worldview (Nyhan, 2016). To counteract pseudoscience and psychomythology, the public needs access to accurate information that provides them with answers and helps them to adjust their faulty predispositions. Unfortunately, researchers have found a growing gap between scientists and the public (Mocarski, 2014). This gap can be attributed to an unavailability of research information, which may be either physically or technically inaccessible for most people. Unlike psychomythology and pseudoscientific claims, which are readily available via the Internet and news media, scientific studies are generally only published in technical journals and are only accessible through a subscription. As the majority of the public would lack knowledge of scientific inquiry, research methods, statistics or research-specific vocabulary, they may find research studies perplexing, intimidating or even threatening (Nyhan & Reifler, 2015). These barriers mean that much of the public, including parents, are unable to easily access understandable and credible research which has a high level of evidence. In contrast, popular psychology is presented in language designed to be easily understood and persuasive and is more readily available and more easily accessible. Furthermore, popular psychology gives parents searching for ways to help their children answers which sound appealing while offering them hope. These claims may also refute scientific knowledge, giving individuals even more reason to rely on and trust information they access via the Internet rather than accessing scientific research.

The inaccessibility of scientific research has meant that the majority of research information is disseminated through individuals or organisations who act as translators for the general public (Mocarski, 2014). Translators of autism research can include professionals such as physicians or psychologists, academic staff and autism organisations, who may also create distrust among individuals seeking information. Researchers have found that both parents and autistic individuals have expressed their distrust of researchers because of past experiences (Pellicano, Dinsmore, & Charman, 2014a). Harrington, Patrick, Edwards, and Brand (2006) found that parents of autistic children were distrustful of medical professionals who they felt had not listened to them or who had been slow in providing a diagnosis for their child and helping them to access appropriate support. In addition, parents have reported that they do not trust education staff who do not acknowledge the parents' knowledge about their children (Webster, Cumming, & Rowland, 2017). Another example of public distrust of autism research is the continued belief that vaccinations cause autism, despite the overwhelming amount of research disproving this claim. Not only has research not changed the view of many people about vaccinations, but it may have actually increased anti-vaccine resistance (Nyhan, Reifler, Richey, & Freed, 2014) due to the insistence of some individuals who have interpreted research information as continuing evidence of the motivation of pharmaceutical companies to sell their vaccines (Yaqub, Castle-Clarke, Sevdalis, & Chataway, 2014).

Researchers have also highlighted a division between the research and autistic communities. Milton (2014) cites several reasons why autistic adults have developed a mistrust of researchers. These include a failure to consider their views in research, research priorities that do not align with the priorities of the autistic community, and a lack of engagement between researchers and the autistic community. Milton recommends that the expertise of autistic individuals needs to be acknowledged by researchers and funding bodies. Pellicano et al. (2014a) conducted a study to ascertain the views of researchers, parents and autistic adults regarding researchers' engagement of autistic individuals and their families. Pellicano et al. found that researchers believed they were engaged with the autistic community, whereas parents and autistic adults did not share this view. Researchers were sceptical about the ability of non-researchers to engage in the research process, while parents and autistic adults spoke about the difficulties they encountered in being included and having a voice in research processes. Pellicano et al. recommended that researches utilise a more participatory and "user-friendly" approach, so that research is not seen as the purview of Ph.D.'s and scientists, but as a process of working together to solve problems that directly impact the autistic community. Not only would this help parents and autistic individuals to have a more ongoing investment and belief in autism research, but it would also make this more accessible and meaningful to professionals working with autistic individuals.

## 1.3 The Impact of Myths

To better understand some of the myths and misconceptions about autism, John, Knott, and Harvey (2018) conducted focus groups with a community sample of non-autistic students and community members. They found that participants disclosed seven beliefs and misperceptions about individuals diagnosed with autism. The first four beliefs were related to social interactions and included the beliefs that autistic individuals: (1) do not want social relationships; (2) do not like being touched; (3) are all introverts; and (4) are unable to notice rejection. The fifth misperception was that autistic people have special talents, and the last two were that they are dangerous or mad. The researchers concluded that inaccurate beliefs about autism were common and probably had an impact on the ways that most people treat or even stigmatise autistic individuals. They also suggested that providing people with accurate information and positive contact with autistic children and adults may help reduce their anxiety about social contact with these autistic persons and dispel some of their misconceptions about these individuals. Although the myths identified by John et al. are just some of the myths that people hold about autism, they do indicate how widespread these beliefs may be and the impact they may have on the ways in which people view and engage with autistic people.

By definition, great myths cause harm, but they can also impact individuals in other ways, both directly and indirectly (Hupp & Jewell, 2015). Lilienfeld et al. (2009) have identified three reasons why myths need to be examined. First, myths can cause direct physical or emotional harm. For example, the myth that vaccines cause autism has resulted in lower vaccination rates and higher rates of vaccine-preventable diseases, like measles and whooping cough. Lower vaccination rates have resulted in more deaths (Flaherty, 2011). Similarly, autistic people have suffered physical harm and some have died when subjected to holding therapy, a therapy based on the myth that autism is caused by limited bonding between parents and their child in the early months of life (Mercer, 2013).

Secondly, myths can cause indirect damage. An example of indirect damage is seen when parents and professionals spend time and money on interventions and strategies that are ineffective or even harmful. Not only does this deplete their resources, but it delays access to supports, which might be effective. For example, believing that autism can be cured, parents, organisations and even governments have devoted a great deal of money to finding a cure. This has consequently decreased the money that is available for supports and services and has led many individuals and families to protest that they need resources to support them now, and not at some point in the future that may or may not ever eventuate (Pellicano, Dinsmore, & Charman, 2014b). Furthermore, the mistaken belief that autistic children and adults do not want social relationships may cause indirect harm by way of excluding them unnecessarily from opportunities for social interaction. Additionally, beliefs that autistic individuals are dangerous or mad may influence the behavioural intentions that people have towards these individuals and may result in them avoiding or excluding them from environments and groups (Csiernik, Forchuk, Speechley, & Ward-Griffin, 2007).

Third, acceptance of myths may impede the ability of individuals to exercise critical thinking and judgement (Lilienfeld et al., 2009). As an example, Matson, Adams, Williams, and Rieske (2013) found that parents with higher levels of education are just as susceptible as less-educated parents to try fad treatments. Myths may result in confusion, feelings of disempowerment and helplessness for parents and service providers about the strategies that will most effectively support their child or client, and may distract them from utilising more scientifically proven approaches (Lilienfeld et al., 2009). Moreover, myths represent beliefs that motivate people to act in ways they view as positive, preventing them from seeing the negative consequences of their actions. Mocarski (2014) contends that with time, these myths and actions become viewed as normal, resulting in long-term detrimental impacts for both individuals and the community.

## 1.4 Transforming Myths

If myths about autism are pervasive, and have a widespread impact, it is critical that these myths be explored to expose the reasons that continue to resonate with people's beliefs and values. To counteract the current negative impact of autism myths, misperceptions and false beliefs must be transformed into new and positive understandings that enable people to gain new insight into current issues and to engage in new ways of thinking about these issues that offer a more positive perception of future possibilities for autistic individuals, their families and support networks. To do this, it is important to examine both the false beliefs regarding autism as well as the origins of these beliefs. This will facilitate a better understanding of how and why different myths align with people's perceptions and needs as well as help prevent future autism myths from arising (Scudellari, 2015). One of the best ways to correct a myth is to link a misconception with the truth. To correct misconceptions about autism, parents and professionals need ready access to accurate, trustworthy research that addresses their beliefs and needs. This information should be presented in easily understandable language, using terms that will help the public make sense of technical information that is often confusing and frightening and enables them to make more informed choices and decisions.

Lilienfeld et al. (2009) caution that debunking myths can backfire, as memory is often selective. Thus, people may forget the new information they have gathered about the myth, creating a misplaced, but increased belief in the myth itself. For example, attempting to correct the vaccine-autism myth may strengthen a person's belief that autism is caused by vaccines as they may not remember the complex science indicating that vaccines do not cause autism, but simply remember vaccines cause autism. In this example, it is important that a wide range of accurate and easily accessible information is made available to the public about vaccinations and autism. This information also needs to challenge the views that make them hold onto current beliefs about autism and vaccinations in order to enable them to trust and be open to incorporating new knowledge. This will allow the facts about vaccinations and autism to be more widely understood giving the myth less authority and credibility.

In a recent study, Gillespie-Lynch et al. (2015) found that by providing college students with clear information about autistic individuals, and accurate information about common autism myths, their misperceptions about autism were successfully changed and their positive attitudes, acceptance and desire to interact with their autistic peers increased. Educating the public is essential if meaningful alternatives are to be explored that will support autistic children and adults. Increasing public knowledge and decreasing misconceptions will also reduce the stigma associated with autism and will facilitate more productive discussions of how to create environments and practices that support and empower autistic people.

Mocarski (2014) argues that reducing the negative impacts of myths involves uncovering the tensions and voices of the people whom the myth silences, as well as the tensions and voices of the people whom the myth supports. To address the needs of both groups necessitates communicating information in ways that enable both groups to find common ground and to develop a shared understanding and alternative perception of the phenomena. It is hoped that examining the origins, research and impact of common autism myths will facilitate a shared understanding between the autistic and non-autistic communities about the true capabilities of autistic people, decreasing the fear that is at the core of many autism myths and creating an alternative perception of the potential of autistic people. Instead of focusing on the ways in which autism is perceived as limiting the lives of individuals and their families, transforming these myths will offer an alternate outlook in which autistic individuals are regarded as valuable community members who are capable of having a voice in constructing supports and services that better enable them to succeed. It is only through constructing new ways of thinking that the myths of autism will be truly discredited, paving the way for the public to not just envision a more positive future for autistic people, but to actively create a more inclusive society in which both autistic and non-autistic individuals are empowered as equal partners.

## 1.5 Conclusion

In conclusion, people use myths to make sense of phenomenon, which they have observed, but do not understand. Myths may have some basis in fact, but contain more inaccurate than accurate information, misleading people into beliefs or actions that have a range of negative and long-term impacts for everyone involved. In the twenty-first century, many myths have developed because of a gap between science and common knowledge, resulting in psychomythology and pseudoscience. One area that has been particularly susceptible to the development of myths is the field of autism. Currently, there are many myths both about autism and about autistic people. These myths often have their source in the emotions of confusion, anxiety and fear as parents and members of the community have tried to understand and support autistic children and adults whom they see struggling to meet challenges in everyday life. This has led to widespread misperceptions in the community about autism and has contributed to stigma and barriers to the enactment of positive strategies for autistic people. To counter these negative perceptions, accurate and accessible information and positive alternatives of thinking are needed.

In the remainder of this book, we will examine the origins of some of the most common myths about autism to understand how and why these beliefs have developed. We will then present the most current research and information to address the beliefs, emotions and tensions behind these myths and will analyse the impact of these myths for the autistic community, their families and the wider community. Finally, we will offer an alternative way of thinking to provide more positive and supportive environments in which autistic individuals can contribute fully and equally as members in a diverse society.

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