Chapter 4

LAYING THE GROUNDWORK FOR AUTISM AND AGING

How to Honor Autistic Essence Toward the Betterment of Society

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Introduction

From the discovery of autism in the 1940s until now, we have seen, and continue to see, an evolving knowledge and changes in understanding and awareness with autism issues. For example, even though we still are not able to point to the cause of autism, we can surmise from research that there are both genetic and environmental components at play (Sandin et al. 2014). With the advent of the Asperger syndrome diagnostic criteria in the 1990s, we began to see a significant increase in the greater attention to aging adults receiving an autism diagnosis. Today we know there is a higher rate of autism in adults than previously thought (Brugha et al. 2011). Because autism was previously understood by behaviors observable in young children, it was thought to be a psychiatric disorder. Today our understanding has evolved to the point where we know autism is not psychiatric, but a complex neurobiological disorder. Even so, the diagnosis of autism remains housed in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 2013). The medical deficit model is used to obtain the diagnosis, and many individuals, especially older individuals with autism, have begun to express their own viewpoints on these issues. For example, initially in the field of autism, knowledge was with the professionals. The public image of autism has been one of a small child rocking, locked away in his own world oblivious to his own surroundings. Over time those knowledgeable about autism have come to include older parents of adult children with autism, and most recently aging adults with autism spectrum disorder (ASD). The public perception of autism, in many respects, remains a negative stereotype.
Historically a diagnosis of autism has automatically translated to a hopeless outcome. Today we have the opportunity to begin to focus on aging adults who live with ASD. We are beginning to see that with the right supports in place, we can and do live meaningful lives. Unfortunately, this is not the case for far too many aging adults with ASD. Though we understand more today than ever before, the support needs of adult autistics are not systematically assessed and addressed.

These tidbits of history not only inform where we are today in the field of autism, but additionally can pave our understanding into the realm of the adult population of autistic citizens. This chapter addresses some of the issues impacting adults with ASD in today’s world. As we discuss the ‘real’ of autism in the lives of aging adults today, we can become more informed. Indeed, as Maya Angelou (1969) said, ‘I did then what I knew how to do. Now that I know better, I do better.’

Children diagnosed with autism live most of their lives as adults and yet we know very little about adults as they grow older with ASD. The good news is that we have much room for improvement in terms of better outcomes for individuals, families, communities, and indeed the whole of society when it comes to the various impacts of autism as those diagnosed grow up, grow older, and take their place in the world as aging individuals, whatever that place may be.

Looking beyond the diagnostic label of autism

We currently use the medical deficit model to diagnose ASD. Many go on to use diagnostic deficits as the framework for thinking about autistic people. Being found lacking and having deficits and difficulties, as measured against typically developing peers, is of utmost importance in the diagnostic realm. However, it is not the sum total of an autistic person. Below is an example of why this is important to understand (Endow 2014a).

Case study 1: My personal experience as an aging person

I get my diagnosis and supports based on what’s wrong with me, what I can’t do, and what my difficulties are in daily life. Most of my life I have been known for who I wasn’t and what I couldn’t do. I am now known for what I can do. I used to be known as a person with autism. I was sought after to provide a first-person account even though I had a masters degree in social work and worked full time. When people asked me to speak at conferences they were often surprised that I sent them my fees. They would say things like ‘But I thought you had autism!’ as if having autism meant that I didn’t need to be paid for speaking. As an aging autistic individual, I think my personal experiences can help provide more understanding and awareness for the larger autism community. I believe my life experiences can help others with autism navigate the aging process.
'Because there is not a good way to measure the things that make me be me those things go unmeasured. Instead I am measured by the yardstick of what makes you be you and am found to be lacking' (Endow 2013, p.44). But then, just like you, I live out my daily life according to what I can do, what I am good at, and what I enjoy in my day.

As I aged, I was able to figure out and implement the supports I needed to make my life work better. Because I am better regulated, I am able to hide most of my autism mannerisms. I am told that I no longer ‘look autistic’ – whatever that might mean. I am now self-employed as an autism consultant. I am also an author of seven books, a DVD, hundreds of articles, and guest author for several compilation books. I am hired to speak internationally. In the past 8 years nobody has questioned my fees. I am now known for what I can do. Rarely am I asked to provide a first-person account these days, but instead, I am asked to provide information from the knowledge base I have accumulated and the books I have written. In addition, my art is now simply viewed as art rather than as ‘special art’ from a disabled artist. I have sold artwork in some local art galleries and have an online art store. This has been a ‘can do’ shift in that my art is known as art because it is what I do rather than my art getting attention because it was created by a disabled person.

In my everyday life as an aging adult it matters a whole lot what I can do because my capabilities have allowed me to earn a living. It matters more in my life today that I can write books, do public speaking, and run my own consulting business than it does that my speech was delayed, I was institutionalized as a child, or have a classic autism diagnosis (Endow 2009a).

It matters today what I am good at and what I enjoy, because this has led not only to me running my own business but in addition is the basis of my friendships with others and the hobbies and interests I pursue. I discovered employment works better when I can manage my own schedule. This allows me to put in the time it takes for me to be regulated (sensory, movement, and emotional systems) to do the various kinds of work I do. Being self-employed initially allowed me to manage my own schedule and avoid the office social scene. Ultimately, designing my work around accommodating my needs as an autistic woman through managing my own business has allowed me career advancement. Together, my work and my friends intersect with my hobbies and interests, bringing me a full life with a depth of meaning.

Autism is my diagnosis, and indeed is so pervasive that it cannot be separated out, and thus I not only have autism as a diagnosis, but I am autistic in my identity. My diagnosis is about who I am not and what I cannot do – a measure of my limitations, deficits, and difficulties. Being an autistic woman is about who I am – a human being who is, who can, and who does—measured by living a full life in her own way in this world.

I had to learn how to outsmart the hard of my autism to live a full life as an autistic. It took several decades. Today, as a 60-year-old autistic woman,
my life is about who I am and what I can do. It is about the real relationships with colleagues, friends, and family. Today I still have limitations, difficulties, and deficits, but they do not define me; instead, they inform me. I can plan my life accordingly, ensuring supports, down time, and accommodations so I can be the human being I want to be in this world. Today I have a full and meaningful life. I am content and happy and I am still just as autistic as I have always been (Endow 2013).

Most of the time people around autistic children focus on what they cannot do so as to make those areas of life better. In doing so, autistic children grow up knowing who they are not. This is not a good basis for living a meaningful adult life because, as aging adults, our work, our friends, and our pastimes are based on who we are, what we can do, and what makes us happy. A meaningful life is not based on diagnostic deficits! And this is even more important as we grow older into mid and later life. As an example, self-actualization is a task of later adulthood. In order to accomplish this milestone of growing older, lifetime fulfillment needs to occur. During my forties and early fifties, just like most people, I was still raising my children and in the production stage of my career. Now that I have reached my sixties, I am looking forward to retirement. (It is important to most people to feel a sense of accomplishment in their life and in their profession as they move into their sixties.) In addition, because of retirement coming into focus, it becomes so important to have a meaningful life outside of my work life. I will soon have time to pursue my hobbies, focus on my art, and spend more time with friends. Because I will have more time, I am happy that my life has become so much more meaningful now than it has ever been before.

The goal is to live a fulfilling life based on many experiences that can make us stronger and wiser as we age. After all, self-actualization, a developmental task of older adults, cannot occur based upon what isn’t!

Knowing autism is a disability and being autistic is a difference

‘Is autism a disability or a difference?’ The way the question is posed gives the impression of a dichotomous choice with one correct answer. Don’t be duped!

When autism is a difference

Many aging autistic individuals would prefer autism to be recognized as a difference rather than a disability. I think of this group as the walking, talking autistics. We can go out in public by ourselves. Some of us are parents, and some of us are grandparents. We are your friends, neighbors, and coworkers. We might seem a bit odd, but we can fit in enough to be allowed a place in the world at large.
Even so, being out and about in the community poses significant challenges. The sensory overload and neurological processing differences dictated by our brain, along with ever-present challenges with communication and conventional social understanding, are huge differences. Even though we can accommodate for them, we are usually exhausted from doing so by the end of the day. And as we grow older, there can be increasing health status issues that may make the adaptations even more challenging.

When we are able to be out and about in our communities unassisted by a hired person, we are expected to look and act like typical people regardless of the challenges imposed by the neurological difference of our autism. Our difficulties and needs are thought to be our own personal problems, even as aging adults. Even though we have an ASD diagnosis, which by definition means we have significant difficulties in many areas of life, others often look at us and ascribe negative intentionality and character flaws to us.

When autism is a disability
For some of us, the way autism plays out in our aging body means we are faced with numerous obstacles to overcome every day of our lives. We may need communication devices, occupational therapy equipment, and to employ personal care workers. For those of us whose autism presents challenges with these sorts of needs, we understand the disability aspect of our autism, especially as we grow older in life.

We often need a hired person to accompany us when we go out into the community or to support us so that we can communicate. In fact, we may require 24/7 support staff. And for some, autism plays out in our body in such a way that people can see it as we approach! Others can see we need help. Rarely do they attribute our difficulties to laziness, lack of motivation, self-centeredness, or any other negative character trait. But because our autism is so visibly noticed along with the significant support we often need, people make other sorts of assumptions about us. Our needs are so obvious that people do not always consider that we also have strengths and abilities along with likes and dislikes. Often we are placed in menial jobs as aging adults (if we are even deemed capable of working), and our support staff is switched around as if people are interchangeable and relationships do not matter to us. We are not often seen as people who have preferences, desires, abilities, skills, and talents, as the time and energy of others are focused on meeting the deficits and needs imposed by our disability.

Case study 2: My personal experience as an aging person

As an autistic person, when I am asked to choose one—either ‘disability’ or ‘difference’—I feel like I am being asked, in essence, which part of me I would like to ignore. When I choose ‘disability’ it means my talents, strengths, abilities, and preferences are ignored. When I choose ‘difference’ my very real difficulties and needs are not only ignored, but I am often blamed for what
others consider my stubbornness in hanging on to negative 'character flaws' (Endow 2009b).

One truth of the matter is that my diagnosis of autism means I have a disability. This is based on the diagnostic criteria present in me that earned me the label of autism. Another truth of the matter is because I have autism I am neurologically different in my way of perceiving, thinking, and being in this world. This difference is so pervasive that it is part of my identity. Just like I am an aging white female, I am also autistic. Who I am and how I interface with the world is autistic, even as I grow older (Endow 2014b).

The truth of disability and difference
These two truths are not mutually exclusive, but instead together create a more robust picture. When posed as a dichotomous question, many are duped into thinking there is a right answer or a real choice when in fact there is none. It is important to understand both truths, especially when it comes to adults. In conclusion, the answer to the question of disability or difference can only be ‘yes!’.

Look at how success is measured
It is a lot of work to look non-autistic, and yet, looking non-autistic is the ticket to sit at many tables. Success is often measured by how non-autistic we can learn to look. The training of autistics to look non-autistic is the foundation of many of our therapies today in the field of autism. Nobody seems to be asking if this measure of success – looking neurotypical (NT) – is success for an autistic, especially as an aging individual.

Case study 3: My personal experience
I think it is not right and good for me, and yet, I choose to expend a great deal of energy inhibiting my autistic ways for the sake of sitting at some of society’s tables. Employment is one such table. Just like all other adults I need to pay the monthly bills, buy groceries, have transportation, and so forth. This all poses quite the conundrum for me.

I spent most of my life trying to figure out the world around me – to fit myself into it in such a way as to feel more comfortable, raise my children, remain employed, and have a few good friends. This all has come at a high personal cost. In many areas of life, I have to ‘suck it up’ and be someone I am not just to have a ticket to participate. After I learned to suck it up I was given more opportunities because I appeared less autistic and more ‘normal’ to other people. Thus, they felt more comfortable thinking of me as competent. As I got more opportunities I had to suck it up more and more. This required
more and more diligence in planning for my regulation needs. Today it takes about 4 hours per day for me to devote to regulation activities so that I am able to do my work, interfacing in an expected manner with the social and communication aspects of employment. I must get up 3 hours before I leave the house and have additional time in the evening. Initially, the ability to suck it up was a bigger and bigger positive over time. Over the past year or more it has come to be a negative influence in my life. The more I suck it up for the outside world the more the bar of expectation to look and act normal is raised. As that happens, the more I need to hide my true autistic self in order to meet the higher and higher expectation of not looking autistic. Many autistic adults refer to this as burnout. Many shut down. Significant depression has been reported among my aging autistic friends. For me personally, I believe it will work out only because I am close to retirement. I am hopeful that I can continue to ‘suck it up’ enough to make it through. While sucking it up once was beneficial in my life, it has recently become problematic.

On occasion, younger autistic adults fault me for sucking it up and being someone I am not. I know this because they tell me so. There is a term I have recently learned called ‘passing’. I am told that when I am ‘sucking it up’, I am ‘passing’. It means I have learned to act as a phony – a sort of pretense at being non-autistic.

In reality, for me it means that when I am in employment situations I expend a great deal of energy to inhibit my natural self. This is necessary to me in order to support myself. Do I like it? No. Even so, I am glad I am able to ‘pass’ when I need to because it has made my life better than when I couldn’t ‘pass’, in that my income is more stable now than then.

Many will argue that all people have to do this ‘suck it up’ to some extent. After all, we cannot just act however we wish when in public. I agree. However, autistics have to do this to such a greater extent that it prohibits many of us from being employed because we simply cannot suck it up long enough each day to be gainfully employed. For me, it means I must pay strict attention to how I schedule my life. I must employ sensory regulating activities and much quiet time in order to be in shape to be able to suck it up and pass when I go out the door to work away from home. There are definitely pros and cons in regards to ‘passing’. As an older autistic nearing retirement I am hopeful I will be able to suck it up a few more years, but I have found that the longer I do this the more difficult my life becomes in terms of being myself versus my copying-of-NT-ways self. There is the cost of personal burnout and sometimes shutdown that can happen as a result of ‘passing’ over several years. Looking forward, I believe it would be in society’s best interests if autistic neurology and the resulting mannerisms and natural ways of being in the world were accepted. This would allow for maximum work contribution and production by autistic people because the energy it takes to continually ‘pass’ could be devoted to work.
I think my life is the best it can be at this point in time with the constraints society places on how autistic contribution is allowed – primarily requiring autistics to look and act as if they are not autistic. I hope younger autistics have broadened possibilities as we go forward. My wish is for more autistics to be able to be the person they are as they grow older in life, utilizing the supports and accommodations they need, without society insisting they hide their very essence at every turn. I look forward to autistics having everyday lives with things so many take for granted – going to school, being part of the community, and having meaningful jobs with living wages along with meaningful relationships. This is the stuff of a satisfying life. All people should have access without society’s requirement of ‘sucking it up’ before a ticket is extended by the majority to those in marginalized groups (Endow 2014c).

Understand ‘losing’ an autism diagnosis

I am a 60-year-old autistic woman who can navigate the world in a way that surprises some people when they find out I have autism. My teen years were spent in an institution because people did not know what to do with my ‘behaviors’ and me. Today I am a self-employed author, speaker, consultant, and artist with a master’s degree in social work — accepting myself as autistic. For much of my life people did things so that I could ‘get better’. During my fifties I came to realize that this was the body I had to live out my life. Just like its gender is female, its neurology is autistic. It was not going to change. I did not need to ‘get better’. I came to accept who I am in this world. I determined to outsmart the hard of my autism to get where I wanted in my life. It is ironic that part of that outsmarting involved copying the ways of NT people so as to look less autistic, but once I could accept myself as whole and complete I had to come to terms with the fact that society does not, at this point in time, accept an autistic as whole and complete. In order to be and do what I wanted during the years of my life I had left, I had to hide the very self I was coming to personally accept. I think this presents a problem to many autistic people in that it is difficult to come to self-acceptance when society does not accept you as an autistic person. We are always expected to act as a typical, rather than an autistic, person. And I believe my life experiences can be helpful to other autistics who are experiencing the aging process.
Question: Did I lose my autism diagnosis?
Official answer: Yes and No

NO, AN AUTISM DIAGNOSIS CANNOT BE ‘LOST’
Technically, once a person is diagnosed with anything that diagnosis becomes part of their medical records. Doctors do not go back in time and erase a diagnosis, or in fact anything, from a patient’s medical records. (This is against the law.)

YES, AN AUTISM DIAGNOSIS CAN BE ‘LOST’
Practically, a diagnosis is derived by matching presenting symptoms to a list of diagnostic criteria for a specific diagnosis. Over time, and with the aging experience, if symptoms are mitigated, the diagnostic criteria may not be observable. Some say this means the person has lost the diagnosis.

The autistic brain

In general, we know the brain is malleable during the ‘growing up’ years. We also know that early diagnosis leads to early intervention, and the outcome of early intervention can be quite positive for some children with autism, in terms of getting autistic children to respond and behave like NT children (if we consider that ‘positive’). What we don’t yet know is if these behavior changes represent a change in the brain — has the child’s autistic brain actually been changed into an NT brain? At this point in time I can find nothing that shows this to be the case.

In addition, nobody seems to be asking if it is a good thing to change autistic brains to NT brains if we had the means to do so. Do we want to wipe out the neurological difference that made our modern world what it is today? How much different would our everyday lives be if the minds of Albert Edison, Thomas Jefferson, and Bill Gates (Devlin 2011) had been changed into the neurotypical?

Case study 4: My personal experience as an aging person

These days I need to go out into the world pose difficulties for me. Most of my life has been spent ‘solving’ these difficulties. I do not take in, process, store, or retrieve information from the world around me like that of an NT person. Lights are too bright, sounds are magnified, and movement is often distorted. I am often side tracked — bothered by or experiencing pain from a multitude of sensory details that nobody else ever notices. My style of thinking is quite literal and concrete. Speed of processing thoughts, ideas, movement, and verbal communication are variable and cannot be hurried up even when I want them to be.
I am exhausted at the end of a work day because it takes a great deal of effort for me to continually stifle my reactions to sounds, sights, smells, and movements that others do not typically notice. I have to particularly pay attention to conventional social mannerisms such as remembering to look at people during conversation, track which words are 'work words' and which words are 'social fluff' words, and respond accordingly. Consciously remembering to look for body language and assign meaning and to ferret out the hidden curriculum others take for granted takes more energy. I work at all this because I like to be able to fit in, and in many respects my continued employment depends on it (Endow 2012; Myles et al. 2013).

Sensory needs change over time. For me, I can count on sensory regulation needs to shift every 1–3 years. Practically, this means that sometimes I spend 1–2 hours daily in a swimming pool, and other times, that time is spent walking. I have always had the constant need for quiet, alone time over the course of my life. It is easier in a sense because I now have a wide menu of things that are likely to work for me. It is harder in a sense because I am now expected to look and act normal all the time, and this requires more hours per day to pull it off.

I have become pretty good at figuring out the right combinations of down time, decreased environmental sensory input, and sensory integration techniques I need to manage various sorts of days. The older I get, the better I am able to guess correctly, but even so, I end my days with exhaustion for having ‘kept up’ with the Joneses (in this case with the neuromajority!).

Some would look at me and say that I lost my autism diagnosis only because I have learned to inhibit most of my natural reactions and responses when in public. I seldom squeal, flap, moan, or make extraneous noises. Because I want a ticket to participate in the world, I have learned over many years how to act like a neuromajority person. And, even though I chose to fit in, I must pay the price for it every day because, even after decades of practice, this behaving correctly still does not come naturally.

Going forward, I believe we need to examine and consider changing our measures of success for autistics. This discussion will undoubtedly be further impacted in the future if science finds a way to determine whether the malleable brain of an autistic youngster can actually become the brain of a non-autistic adult. Until then, we need to ask if the outcome of being indistinguishable from peers really is as successful as we imagine it to be. And if so, for whom or for what is it a measure of success (Endow 2014d)?
Considering the breadth, the depth, and the importance of choice when it comes to inclusion

I love the idea of inclusion. It is right and good. It is very important. But sometimes this setup doesn’t work well for me. I think this is a very important issue, especially into mid and later life. I am not able to access my thoughts and words in real time. Even a quiet environment, with several people in the same room, does not necessarily allow me access to those people or even to my own thoughts. Sometimes this sort of situation can propel me into shutdown or meltdown mode. In fact, now that I have access to the typical world and experience an inclusive adult life in my community, I am discovering that I don’t always want to participate in the typical world. If inclusion is good and right, then why is this?

A breadth of inclusive experience

As I ponder this question for myself as a 60-year-old autistic, I realize the world is run according to the majority. This means a neurotypical NT brain is what is behind the conventional constructs of our society. Inclusion looks the way inclusion works for the NT majority. Inclusive opportunities, and indeed all of inclusive education and life, happens NT style. It is what we have. It works for NTs and it even works for me some of the time. It allows a breadth to inclusive experiences (Endow 2013).

A depth of inclusive experience

At other times I need to honor my autistic neurology. While I love being part of the everyday fabric of life in my community, I also need to spend time living my life with other autistics. As my acceptance in general depends on my ability to look normal, it requires me to inhibit and hide everything that is natural to my autistic way of being. I find that the more I need to be my fake NT look-alike self, the more I need the true community of my autistic community where I can be who I am without being faulted, blamed, or given decreased life opportunities due to my ways of being different from the majority of human beings. I believe these are important issues for other aging individuals with autism. This is where I have found the depth of inclusion my heart and soul have searched for my whole life. It feels like home to me. It is the place where I do not need to inhibit my natural noises, flaps and extraneous movements, and moans. I do not need to be mindful of the hundreds of social rules of NT society. I am free to be my true self. My autistic friends do not judge my intelligence, my potential contribution, or my human worth by my unconventional mannerisms. I belong, just as I am, in my natural state. I am accepted and loved for my whole self – not just for my NT look-alike self.
The breadth, the depth, and the importance of choice
For me, it is quite important to know how to get along in the world at large. I love the freedom of being able to walk in and out of any place in my community and fit in so as to appear to belong. I love being able to take my place in the world at large. I am grateful to have this choice because it hasn’t always been this way.

Additionally, a different and perhaps more important inclusion experience comes from the community of my autistic friends where all of me – including autistic traits and mannerisms – is understood and cherished. This is the place where I have the most fluid access to the best of my being, likely because I do not have to inhibit my natural autistic self. To me, this is a treasured wonder. This points to the importance of social networks for many individuals as they age.

From a history of marginalization
At the end of the day, I ponder the inclusion situation through history. Being ‘othered’ much of my life in ‘special’ settings never felt like inclusion to me. It felt like being shoved to out-of-the-way places of ‘less than’. Then later, given only the opportunity for inclusion NT style, I was left wanting and longing for something I did not understand until I met other autistic adults.

Toward a future of comprehensive inclusion
I believe we may come to discover in the future that, to thrive and to be all that we can be in mid and later life, we aging autistics will need both the breadth of NT inclusion and the depth of autistic inclusion – two distinct and equally important styles of inclusion. As autistics, we also need to be empowered to choose how this mix best works for us in our given autistic bodies. My needs wax and wane over time, and as an aging individual, it remains constant that I need access to both inclusive environments and to be able to choose the mix that serves me best, knowing those needs will not remain constant. This allows me to belong and to participate fully in the human race (Endow 2014e).

Moving beyond awareness
Today it is hard to find people who are not aware of autism, but it is difficult to find people who understand autism and who accept autistic people, especially in the context of the aging experience. Before one says that one ‘accepts’ autistic people, consider the following:

- People who are aware of blindness do not expect blind people to try harder to see.
- People who are aware of seizure disorders do not expect those who have seizures to try harder not to have seizures.
- People who are aware of paraplegia do not expect paraplegics to try harder to walk.
- People who are aware of autism do expect people with autism to try harder to act like they are not autistic.

This is why autism awareness is no longer enough; looking indistinguishable from peers may not be a valid goal, and rethinking the status quo is necessary as we go into the future as aging individuals. Please accept us. Our autism neurology is part of who we are in this world. As such, we cannot simply ‘suck it up and get over it’ (Endow 2014f).

Autism bestows upon each of us a unique mixed bag of blessings and challenges. Awareness means you see the challenges, the behaviors, the not fitting in with the rest of society. Acceptance means you stand with us in learning to use our strengths to outsmart the challenges autism puts in our way so we can be and do all we want in this world. Please work with us — not on us. Together let’s forge ahead for the betterment of all of society. Autistic or not, the aging experience includes all of us!

**Conclusion**

This chapter lays the groundwork for how we can forge ahead together, honoring the autistic essence in the context of aging, and toward the betterment of society, by:

- looking beyond the diagnostic label of autism
- knowing autism is a disability and being autistic is a difference
- looking at how success is measured for autistic people
- understanding ‘losing’ an autism diagnosis
- considering the breadth, the depth, and the importance of choice when it comes to inclusion
- moving beyond awareness, and focusing on acceptance of all autistics — including those of us who are aging — realizing we have not outgrown the autism.

I look forward to the day where the autistic adult sentiment ‘nothing about us without us’ will be thought of as ‘old school’. This will be a day where autistics are not separated out and then brought back in, but instead where we are part of the fabric of society from cradle to grave being the people we are, contributing, living, and being supported in realistic ways toward the benefit of all of society.

**References**


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Chapter 5

AGEING WITH AUTISM

Improving Health, Improving Rights

Michael Baron and Saskia Baron

Introduction

In London in the summer of 1961, after taking my 4-year-old son to various baffled specialists, I (Michael) heard the word ‘autism’ for the first time. Timothy was a handsome little boy who did not sleep much, did not talk except to echo favourite phrases, and who threw ear-shattering tantrums when faced with novelty. He was clearly not like other children, and in those days, professionals’ advice was to send him away to a long-term sub-normality hospital. Instead, we found other parents with autistic children and started a campaigning charity and a school. Over the years that school turned into a group of schools and then residential communities when it became clear that some of our autistic young adults would need lifelong support. The National Autistic Society has grown from a tiny, parent-led voluntary group to an employer of 3500 staff. In 2014 it had an annual income of £98 million and offered advice as well as ran campaigns, schools, and adult services, all with the aim of improving the quality of life for everyone on the autism spectrum in the UK.¹

In the half century I have been involved with autism, I have seen it evolve from a seemingly rare condition affecting 1 in 2500 (Lotter 1966) in the 1960s to today’s estimate of 1 in 100 in the UK (Brugha et al. 2007) and 1 in 64 in the US (Baio 2014). There are many anxious debates about possible causes and rising prevalence. To quote Thomas Insel, then director of the National Institute of Mental Health in the US: ‘Are there more affected or more detected?’ (Insel 2012). But one concern rarely gets aired: What will happen to autistic adults like my son (who is 60 years old and has intellectual disabilities and high support needs) as they reach later life and lose their parent advocates? This is what we are concerned about here.

One of the reasons that the rate of autism has grown is increased awareness; when Timothy was first diagnosed it was a relatively new word. Other professionals

¹ See www.autism.org.uk for more information.