Chapter 27

CURRENT AND FUTURE PERSPECTIVES

How Do We Measure Up?

Valerie Paradiz and Xenia Grant

Introduction

I am Valerie Paradiz. I am 52 years old and was diagnosed with Asperger syndrome when I was 40 years old. I'm also a parent of a young man (25 years old) named Elijah who was diagnosed with autism when he was 3 years old and struggling with a seizure disorder. Elijah is in his mid twenties today, and he works and lives on his own. Together, we have traversed more than two decades, witnessing the breathtaking emergence of a social movement among autistic people, their families, and the professionals who work in disability fields. In the space of those 20 years, as the number of diagnoses soared, we saw autism become a presence within the broader disability community. Along with this, we also watched autism become a force to be reckoned with in mainstream culture, which continues to grapple with who we are and what we have to offer.

When I was invited to contribute to this book, I knew I wanted to share with readers the significance of the moment that we as people with autism, as parents, as professionals, and as educators face right now. Daily, I see examples of how we seem to teeter on the brink of success or failure in our combined social movement, be we autistic or not. In this chapter, my co-author and I explore how we view the potential success and failure of the autism social movement, as well as what the future might hold for people with autism as we are born, live out our childhoods, become adults, and age into older life. I believe many answers to success lie within autistic individuals and the groups of autistic people who have evolved these past two decades in their self-awareness and in their experience negotiating what we call the 'autism community'. I will also share with you my own personal perspectives of autism and the aging process. In order to convey the unique crossroads we stand at together as people with autism and those who love and support us, I'm joined by my co-author,
Xenia Grant, whom I have known since the earliest years of the autistic self-advocacy movement.

I am Xenia Grant (50 years old) and I was diagnosed as having autism at 36 years old. When my mother was in her fifth week of pregnancy, she had German measles (rubella), a virus that can cause damage to the fetus. I believe that virus kicked in something that altered my brain development at that early phase in the first trimester, and that is why my neurology is different. I hit all my developmental milestones late and was not verbal until I was nearly 4 years old. It was said by professionals back then in the late 1960s that I would not be able to talk, read, or write, and that my IQ was under 50. Before 1975, in Missouri, a child had to have an IQ of over 55 to even get educated. I come from a huge family (four sisters and three brothers), and my family worked with me. I went to regular schools all my life, then went to college and graduated with a degree in political science. After graduating from Maryville University in 1987, I moved to New Jersey because that state had an independent living program that would help me to learn life skills. Twenty-five years ago there was little knowledge about autism and people who were like me. Eventually I moved to St. Louis, went to secretarial school, and got a degree in medical transcription. Eventually, I did land a job in that field, but my auditory processing differences led me to not having that job. I never went back into that field and have worked at various jobs ranging from telemarketing, to shelving books, to data entry, to respite care, to cleaning apartments for people who had disabilities, to my present job at Goodwill as a processor in the e-commerce department. Right now, I am living independently in Denver and moved to Colorado from St. Louis after 3 years of marriage. (Yes, autistic people get married and get divorced.) The things that interest me the most are cats, history, current events, comparative economics and religions, and Orthodox Christianity. I end my introduction by saying my faith tradition influences my daily life in many ways.

How do we measure up?

In this chapter, we look at present and future perspectives with regard to the mid- and later life of adults with autism. Perspectives are important. They are a reflection of who we are as a society and how we wish to treat people with autism at any given moment in time. In order to understand current perspectives and offer our thoughts on shaping future ones, we turn to the social movement model to assist us. It is likely that many readers who have read this book and have reached this chapter might consider themselves part of a social movement. You might be a parent or family member who believes in advocacy for your child or other loved one on the spectrum. You might be a professional who advocates within the fields of research, education, or services. You might be a person with autism advocating for yourself and for others on the
spectrum like you. All of these activities are meaningful, but sometimes we run the risk of isolating from one another and viewing that our own advocacy is the only advocacy, the only path. This creates silos of activism that ultimately do not serve us as a community but instead can lead to deep rifts. Unwittingly, we run the risk of dividing and conquering ourselves.

Researchers have identified four common phases of social movements to examine how they emerge and grow in purpose, as well as how they succeed or fail (Christiansen 2009). We can apply those four stages to our own activities and perspectives within the autism community and ask ourselves, how do we measure up today, and where are we headed? The four stages of a social movement that guide our analysis are:

1. emergence
2. coalescence
3. bureaucratization
4. decline/institutionalization.

**Emergence**

Autism isn’t something a person has, or a ‘shell’ that a person is trapped inside. There is no normal child hidden behind the autism. Autism is a way of being.

— Jim Sinclair (1993, p.3)

Many people with autism view the publication of Jim Sinclair’s 1993 essay, ‘Don’t Mourn for Us’, as a watershed moment in the disability movement. It was and is a symbol of our emergence as autistic activists and of the emergence of a social movement. In social movement research, ‘emergence’ is described as ‘the first stage of the [movement’s] life cycle’. This is a period when activities are ‘very preliminary’ as early participants begin to express unhappiness with a ‘policy or social condition’ (Christiansen 2009). Jim Sinclair’s essay drove home the concern with social conditions that people with autism were experiencing. Not only did he point out that the perception of who we are as people was misguided, but he also unveiled the significant rift that existed between many children with autism (including adults who were once children) and their parents. At the time, the parent social movement already had established a strong foundation, with organizations such as the Autism Society of America, founded 28 years earlier in 1965, at the forefront. In this way, the earliest autistic advocates found themselves initiating a movement that struggled for a voice and identity within an existing movement that threatened to subsume it.

In the early 1990s, some self-run, fledgling organizations began to emerge. Their purpose generally had to do with supporting us as people with autism in a world that had little understanding and patience. Some of these groups were focused on specific
human rights issues, such as restraints and the right to communicate with tools, such as letter boards or technological devices that generate speech. The Autism National Committee (AUTCOM) was founded in 1990 ‘to protect and advance the human rights of all persons with autism, PDD, and related differences in communication and behavior’ (AUTCOM 2014). Some of its core activities include an ongoing focus on human rights issues, such as abuse of people with autism in segregated settings – for example, the Judge Rothenberg Center in Massachusetts and its use of shock treatment and aversives. By the mid 1990s, AUTCOM’s vice president was a person on the spectrum, and in this century, two of its presidents to date have been autistic, both of whom use AAC devices as the primary means of communication.

Another important event of the early movement took place in 1991, at the Autism Society of America’s annual conference in Indianapolis. That year, several self-advocates from across the country gathered for the first time as a group, leading to the development of important self-run organizations. In 1992, Autism Network International (ANI) was founded. Pre-dating the Internet by a few years and publishing its own print newsletter, *Our Voice*, ANI worked tirelessly to connect with adults on the spectrum in the United States and abroad. Autistic leaders in places as far away as England and Japan began corresponding with autistic adults in the United States, and by 1996, ANI had initiated Autreat, a self-run retreat-style conference that became an annual event on the East Coast. On the West Coast, AGUA emerged, founded by Jerry Newport, who, after Temple Grandin, was one of the first people with autism to serve on the board of directors of the parent-run organization Autism Society of America. During this early period of emergence, meetings among autistic leaders were few and far between, and our communication was by telephone or by letter writing. However, with time the Internet grew, as did our momentum. Today, there are many more advocacy groups whose leadership and members are people with autism.

**Coalescence**

It is a peculiar sensation, this double consciousness, this sense of always looking at oneself through the eyes of others, of measuring one’s soul by the tape of a world that looks on in amused contempt or pity.

– W.E.B. DuBois (1903, p.3)

‘Coalescence’, also referred to as the ‘popular stage’, is the next phase in the cycle of a social movement, particularly as it becomes more ‘organized and strategic in... outlook’. Also in this period, ‘leadership emerges and strategies for success are worked out’ (Christiansen 2009). Autistic people have moved solidly into this stage, in spite of the early challenges posed in the 1990s. Today, there are organizations formed by autistic people with boards and members who are autistic or majority autistic. Many of these serve as either support groups or human rights organizations. The Global Regional Asperger Syndrome Partnership (GRASP), founded by Michael John Carley, has established chapters and adult peer support groups nationwide.
Following GRASP’s lead, Ari Ne’eman and the Autistic Self Advocacy Network (ASAN) organized a national coalition of autistics who engage in political and legislative activism at local, state, and national levels. In 2009, Ne’eman was appointed by President Obama to the National Council on Disability, becoming the first autistic person to serve in this federal capacity. In 2011, the Autism Research Institute was the first national autism organization that emerged from the parent–professional movement of the 1960s to launch a new autistic-led division, the Autistic Global Initiative (AGI). AGI’s focus is to build collaborations across the various stakeholder groups in the autism space, while developing and disseminating courses, programs, and curricula that are created and informed by experts with autism. As in the early 1990s, the issues many self-advocates and self-run organizations focus on today derive from continued, firsthand experiences of having our or other autistics’ personal and human rights denied. Today we work tirelessly as ambassadors of a culture and of a knowledge base that has yet to be tapped to its fullest potential.

Moreover, our adult generation on the spectrum has become a model for younger generations of autistics. Just as we grew up together and mentored one another through the 1990s and into this century, we find ourselves fostering young adults into the movement, sharing our 20 years of experience as we do so. We like to think of next generation as the ‘second wave’ of autistic advocates. They are young leaders, actively mentoring and empowering their own generational peers, thereby bringing originality, richness, and depth to the movement today. The AGI plays a significant role in developing future leaders with autism through its Young Leaders’ Division, which is led by Sondra Williams, recipient of the Governor’s Courage Award of the State of Ohio in 2013.

In spite of the coalescence of the autistic movement, the tension between the parent–professional communities and that of self-advocates that existed in the 1990s persists. However, it has taken on a new form. Sometimes this tension has led to healthy and democratic compromises and collaborations, such as the development of the People on the Spectrum of Autism Committee (PSA) at the Autism Society. This council, established through the hard work of veteran autistic advocates Stephen Shore and Ruth Elaine Hane, consists strictly of autistic representatives – the majority of whom are parents or professionals as well – providing technical assistance internally to the Autism Society, as well as to its chapters and constituents.

In other instances, the tension between parent–professional agendas and those of autistics are at cross-purposes. These are hard moments for us to endure or to witness our peers live through. In such moments, as people on the spectrum, we move into that difficult double consciousness of experience that W.E.B. DuBois so aptly describes in his depiction of African Americans in the years following the Civil War and Emancipation, measuring our souls ‘by the tape of a world that looks on in ... contempt or pity’ (DuBois 1903, p.3).

There is no doubt that parents, professionals, and autistics have moved forward together in the past 20 years, but in this critical stage of coalescence for autistic people, how does our broader, combined social movement measure up today? This is the crux
of the issue for many autistic leaders right now as, daily, we go to work with our experience, education, hard-won skills, and powers of challenge and negotiation, just as any parent or professional who is an advocate does. Since 2005, somewhere in the world, Autism Pride Day is celebrated. And during April, Autism Awareness Month, autistic people are blogging and making our views and voices heard throughout the world. We are consolidating more deeply, making mainstream society aware that autistic people exist, and that we are here to stay.

Bureaucratization

Everything depends on what is in our hearts.

– Daisaku Ikeda (Ikeda 2014), Buddhist scholar

The third stage of social movements is called ‘bureaucratization’. It involves ‘higher levels of organization and coalition-based strategies’, as well as a departure from reliance on ‘inspirational leaders’ (Christiansen 2009). Often, this requires strategizing among several groups or organizations, with expert staff to carry this out. To a limited degree, autistic individuals have achieved this step within their own movement and in partnerships with national disability organizations such as Self-Advocates Becoming Empowered (SABE) and the Arc, but a more meaningful effort lies ahead. Even within our own ranks of self-run initiatives, there are unproductive examples of divisiveness and even disconcerting accounts of autistics denigrating other autistics, rejecting dialogue with one another because our different agendas do not match, or disregarding that the variety of expression of autism is a fundamentally connective experience. This is our Achilles’ heel and a sticking point that keeps us from reaching the large population of children and adults with autism who might become more empowered and happier in their lives due to higher-level strategy efforts.

As co-authors, we feel the spiritual aspect of our lives can play a critical role in addressing such complicated issues as those presented here, in the same way, for example, as the American Civil Rights Movement was bolstered by spiritual practice and leadership. We have witnessed how religious and spiritual traditions can guide autistics in their advocacy and in their everyday life. A good example is Jim Sinclair. Jim is Jewish, and that tradition influenced the development of Autism Network International (ANI) and its basic organizational tenets. Similarly, Donna Williams of Australia turns to Eastern religious traditions to guide her writing, art, and work. Valerie Paradiz practices her Buddhist faith, Sōkka Gakkai International (SGI), chanting each morning for peers and colleagues both on and off spectrum and contemplating the responsibility of leadership.

Xenia Grant is Eastern Orthodox, and that ancient Christian tradition guides her in her autism work and advocacy. For example, as the Denver facilitator of the Global Regional Asperger Syndrome Partnership (GRASP), her goal is offering hospitality and ensuring the members feel welcome. Meetings take place at her apartment because
many autistic people feel unwelcome in many environments. At GRASP meetings, they feel at home and a part of something bigger than themselves, which Xenia feels is a first step towards political activism. People need to feel that they are part of the wider world before participating in it. Another way her faith tradition helps is that she takes every person as an individual, made by the Hand of God. 'We are made in His image, autism and all,' Xenia writes, 'and I believe that when we discriminate, abuse, and look down on others who are different, we are crucifying Jesus again and again' (X. Grant, personal communication).

Perhaps the higher level strategy we need in order to leverage a movement that has yet to reach the majority of its autistic constituents will be the work of the next generation of autistic leaders, for it demands skills that characterize the third stage of a social movement: 'trained staff to carry out the functions of organizations'. This requires knowledge of negotiating the autism space, including negotiating the parent–professional space and the difficulties and opportunities it poses. It also requires more access to quality education and the funding of administrative, managerial, and executive positions for autistic people. Clearly, we cannot develop into this third stage without significant collaboration across all stakeholder groups. Building durable collaborations between the autistic and parent–professional realms and aligning ourselves in one voice for the most critical advocacy efforts likely are the only way forward.

Decline

Parents should love their children as their children and not as their idols. That is to say, they should love their children as they are and not how they would like them to be – to be like them.

   – Elder Epiphanius of Athens (2003, p.3)

The final phase of a social movement is decline, also described at times as 'institutionalization'. Decline 'does not necessarily mean failure for social movements'. In fact, sociologists have identified at least four pathways that are possible in this last stage of a social movement (Christiansen 2009):

1. repression
2. co-optation
3. failure
4. success.

Repression

The wish to end or prevent repression likely is the leading motivator for many of the advocacy initiatives carried out by autistic people today. With this comes the deep knowledge that if we did not challenge acts of repression, we would see the decline
of a hard-won evolution within mainstream culture that began over 20 years ago. As a simple example, the authors of this chapter still remember the time when no one used the word ‘neurotypical’ to describe mainstream neurological culture. Today, it has been adopted not only by autistic people but also by most constituents within our community, including parents and professionals. In fact, few question this word any longer, and in general we are shown great respect when others do use it, for they are choosing to neutrally acknowledge our differences, without value judgment or repressive suggestion.

The threat of repression crops up in many ways. Sometimes it occurs due to ignorance, other times it occurs due to the stress of supporting a person with autism or to the unwillingness to relinquish a power that should be ours as humans. As an example, repression sometimes (not always) is experienced by autistic students in school classrooms; the relevance of this for adults with autism is that, oftentimes, along with the experience of being repressed in school, we also experience trauma, leading in turn to challenges that, if not properly addressed, can affect our access to education, work, and relationships.

A common repression narrative shared by many on the spectrum is that our sensory differences were minimized, disregarded, or punished when we were children in school. Autistic children, and many autistic adults, often lack the words and the advocacy skills to share their concerns about sensory difficulties. (Indeed, in classrooms today, few children on the spectrum are provided with these basic tools.) As a result, they may be labeled as a ‘behavior problem’ and provided with a behavior plan that does not address the sensory accommodation needed. Instead, the plan contorts the child’s experience of the sensory disability into a behavior he is responsible for and must change. This is tantamount to expecting that an individual with a mobility difference who uses a wheelchair should one day walk, if she only makes the effort.

This story may seem subtle, or even negligible, to the outsider who does not experience sensory challenges in the way that we often do. For the person with autism, it is a story of repression in that one is rendered powerless and fixed within the lens of someone else, rather than respected as a human being. For us, it feels as if there is no way out. We are at great risk of physical or emotional abuse.

Repression also can be found in the use of aversives, causing escalation of ‘behavior’ that is deemed ‘autistic’ by the professional or parent, rather than as a result of the brutality of the aversive itself. This is why so many of the earliest autistic activists spoke out against the use of aversives: their pain began in such situations. In this way, many of us have become hyper-vigilant in our activism, as we strive to prevent the decline of our movement due to the very repression that motivated us to take our first steps those 20 years ago. In the future, we see this aspect of autistic advocacy growing ever and ever stronger, especially as our numbers grow stronger in our education, our employment, and our self-determination.
Co-optation

'Movements can also decline, if their organizations are highly dependent on centralized authority' (Christiansen 2009). For autistics, this centralized authority often presents itself in the parent and professional spheres, for the movements related to those sectors are further along the path of development and thus more bureaucratized and centralized, more likely to co-opt our efforts. Xenia Grant provides a personal illustration of this:

I will speak of my experiences with this and hope that you, the reader, can expand on this and think of how it is done to others. In the twenty-first century, I was on the board of the Autism Society of Colorado (ASC) and appointed by Governor Ritter to the Autism Commission of Colorado in 2008–2009. I was the first autistic person to be on the board of the ASC. I faithfully attended its meetings and did my best on the various committees I was on. One of the things I learned is that when an organization has just one member of the community it is said to represent serving on its board, tokenism can arise. Tokenism means to me that I am there representing my people, but the ideas that I bring up may be ignored or not taken seriously. Also, it means that other members may end up thinking that my view is how all of us autistic people view things. I know that is not the case. How I view an important issue may be the opposite of how someone else with autism views it. Sometimes (not always) at the board meetings, I felt as though my ideas were not listened to. All the while, my focus and input was on the urgency of addressing problems for adults with autism. When I was on the Autism Commission of Colorado, I learned from the testimony given that there are few services for adults and that in rural areas, they are almost nonexistent. Services for adults with IQs over 70 were almost zero. I also learned that getting autistic adults together on anything is like ‘herding butterflies’, as a member of the council used to say to me. I was told that communication is not our strongest suit, and in politics and activism, communication is key in getting the message across. So, the question I ask of readers is this: How do autistics advocate for what we know is necessary, when our very voices become co-opted by others? Do we need to be like you in order to serve? Why do you invite us to serve? (X. Grant, personal communication)

Conclusion

Dwell in possibility.

— Emily Dickinson

Both Xenia and I are considered at mid-life (in our early fifties) and we both have appreciated how both the professional and the personal issues of autism can change
over time. But before we conclude with a few personal perspectives with the aging process, we examine the process and potential with a social movement and autism issues. So far, we have looked at two pathways that can lead to the decline of a social movement. Now we turn to the remaining pathways of success and failure. By definition, if a social movement ends in success, it has achieved its goals. For example, the women’s suffrage movement ended because it was successful: women got the vote. On the other hand, failure of a social movement can occur because of ‘organizational strain’ and ‘collapse into different factions’ (Christiansen 2009).

**Failure**

Failure within the autism community is best represented by the isolated silos of advocacy we discussed at the opening of this chapter. Those silos have existed as various camps within the parent–professional space and are dictated by their specific agendas. Indeed, instances have occurred when the autism community has been criticized at the federal level as a movement that cannot easily come to consensus among its own stakeholders, thereby undermining its efficacy in Washington. Autistic people are deeply affected by this divisiveness. Sometimes we are polarized within our own ranks, too, doing ourselves a disservice. More often, however, we are affected by the amount of effort and money expended by parents and professionals, allegedly on our behalf, without substantially breaking down the walls that keep us from engaging in a shared advocacy process. Indeed, we watch the parent–professional space with attention when it moves through its fractious periods with itself, teetering on failure due to fragmentation. And we look on knowing that without our critical experience and knowledge, solutions may not be found, leading to failure for all, autistic and non-autistic alike.

For people with autism, failure of advocacy is when we autistic people are looked at as ‘less than’ by the non-autistic majority. Sadly, in this day and age it is all too common for non-autistics to deny our humanity because of our differences, and it is most noticeable with those of us who use AAC devices or facilitated communication (FC) as the primary way of speaking. When the validity of a person’s communication is in doubt, that individual is being denied their personhood. Common stories shared by people who use AAC and FC tell of the deep hurt they feel when others don’t believe the words that come from their hands or from the machines that produce their words. We cringe when we witness people who express suspicions about facilitator influence. Many autistics don’t feel heard or listened to, and it is exponentially harder for those who don’t use their mouths to speak.

Failure in the movement is when autistic people are shut out from the community. Many adults want to live, work, recreate, and contribute to the world at large. Talent is lost when we are not part of the community, and when our advocacy efforts are not integrated as a critical aspect of achieving progress. When we are in separate schools and in separate living spaces, when we are not invited to serve and lead as who we are, creativity and perspective are lost. Autism activists are raising their voices, whether by
mouth, finger, or device, saying, ‘We are talented, we are worthy, and we are here to stay.’ It is devastating when advocacy organizations say we are missing from the process because we socialize and behave differently. It is devastating to be likened to being held hostage by our brains because our perceptions aren’t the same as those of the non-autistic population. Failure will lurk in the broader autism social movement, so long as it is unable to include the very voices, processes, and knowledge that people with autism possess. We are the key to the failure or success of the autism social movement.

Success

Success is when autistic people are treated as a part of life and are not segregated. Separate but equal is never equal. We will see success when autistic adults are in jobs as varied as the rest of humanity. We will see success when it is no longer a rarity to see an autistic person in the workforce, especially in high-paying and leadership positions. We will see success the day when accountants, cooks, bus drivers, astronauts, economists, doctors, social workers, and interior designers find it ordinary to have autistic people working side by side with them, and not just an oddity, not just because of affirmative action. Success is when autistic people with proper supports are living lives in the community to the best of their ability. Success is when our supports for living are no longer viewed as unusual because we don’t fit the mainstream paradigm of independence. Success is when we are viewed in neighborhoods, places of worship, universities, movie theaters, and shopping malls as just part of the environment, instead of as an anomaly. People with autism hold the key to many questions that seem unanswerable and to many problems that seem unsolvable. We are an untapped source of solutions, for we hold the practical knowledge of what it is that undermines our learning, productivity, and citizenship. Bringing this wealth of experience directly into the current issues we grapple with as a total community will strengthen the possibility of improving education, housing, employment, and social participation for adults. Dare to dwell with us in this possibility.

Personal perspectives on aging and autism

by Valerie Paradiz

At mid-life, my personal perspectives of autism and aging and social movements have both consistencies and differences in the past two decades. The constant over time is the dedication to supporting the autism self-advocacy social movement. But this is nuanced by subtle changes over time as I have aged. For example, in my earlier years as an advocate for autism issues, I was primarily focused on autistic activism and perspectives and admittedly quite rigid and one-dimensional about research and professional views. Now that I am older, I have become more flexible in my awareness and knowledge and I embrace a wider variety of perspectives. This is probably due to my ‘wearing many hats’ as a mother (parent) of a son diagnosed with autism,
myself (aging adult) as diagnosed with Asperger's syndrome, my role as a professional with an autism initiative, and being involved in the social movement for so many years. I am also experiencing sensory challenges as I age, and this has led to new coping and adaptation patterns at mid-life. Thus, it's a relief to see that sensory issues associated with autism have become more prominently featured with the DSM-5, which can help with intervention goals.

At this point in my life, I have found that mentoring younger adults with autism in leadership development is a very rewarding experience. I can offer my experience as a teaching opportunity, but the key is to share the ways in which advocacy can be empowering to the next generation of leaders. Finally, it is important to share the autism aging experience, and I have become more prudent and open to the perspective that 'good things take time', and this certainly applies to individuals and social movements that develop and mature through 'waves' – that change over time.

References


Chapter 28

QUALITY-OF-LIFE OUTCOMES OF AGING ADULTS WITH AUTISM AND THEIR FAMILIES

Elizabeth A. Perkins

Introduction

So often we hear the phrase ‘quality of life’ (QOL), but what do we actually mean by having a good QOL? What are the different aspects that should be considered when thinking about QOL? The answers are as diverse and complex as our aging process. This chapter discusses QOL, the application of QOL to older adults, and what we know about QOL in aging adults with autism and their caregivers, and concludes with planning and promoting successful aging.

Conceptualizing quality of life

Felce and Perry (1995) described QOL as an elusive concept that encompasses various assessments of societal and community well-being as well as individual well-being. Quality of life is thus a broad concept with many domains. Distilling the research of many, Felce and Perry concluded that there are five general domains that should be considered. They are physical well-being, material well-being, social well-being, development and activity, and emotional well-being. Within each of these domains, there can be further delineation. For example, the World Health Organization (1948) defines health (i.e., physical well-being) as a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity. Therefore, even when considering the concept of physical well-being, there are many factors beyond one’s own bodily processes that contribute to good health, including interconnection with others. Thus, QOL domains are also interrelated and connected, and can impact each other. I have a personal bias for promoting good health above all others, as health underscores a person’s ability to enjoy and participate in all of life’s activities. However, some may argue that ‘development and activity’ in the form of access to education
and promoting self-determination are equally important factors to promote a good QOL, especially with adults with autism. This underlies the importance of subjective assessment that takes into account the values and aspirations of the individual (Felce and Perry 1995). However, research, by necessity, has to aggregate data and compare it with a recognized standard of consensus determined by researchers, who draw upon the societal values of their communities and cultures, as well as economic indicators. We can use benchmarks to gauge the general population, but there is always going to be individual variation due to personal preference, motivation, and life goals. Fundamentally, every person has the right to self-determine what are necessary components to help ensure a good QOL. Support workers and caregivers can also help ensure that person-centered practices are undertaken to promote possibilities and choices.

Aging and quality of life

How does aging impact QOL? Rowe and Kahn (1997) introduced the concept of ‘successful aging’, which I believe can equally be thought of as having a good QOL as an older adult. Rowe and Kahn described successful aging as a) low probability of disease and disease-related disability, b) high cognitive and physical functional capacity, and c) active engagement with life. The first two criteria are undoubtedly influenced by pre-existing abilities and healthy lifestyle choices. But fundamentally they set the stage for one's capacity to be actively engaged in life. Rowe and Kahn emphasized that the two most important forms of active engagement are interpersonal relations and productive activity. Here again, there emerges recognition of the importance of connection between domains that impact successful aging and, more importantly, connection to others.

Family quality of life and reciprocity

Many adults with autism and other developmental disabilities live with family caregivers and will do so for the majority of their lives. The need to consider the family unit as an important component of QOL when evaluating and administering support services led to the development of assessment tools to measure family functioning, including the Beach Center Family Quality of Life Scale (Summers et al. 2005). Domains of this particular scale include physical/material well-being, emotional well-being, parenting (e.g., family members help individuals to learn to be independent), family interaction (e.g., spending time together), and disability-related support.

The role of reciprocity in these caregiving relationships is also important to consider. My own research has found that emotional and tangible reciprocity (e.g., help around the home) between adults with intellectual disabilities, including autism, and their older family caregivers does exist (Perkins and Haley 2013). Indeed, some older caregivers report receiving more than they give in emotional and tangible reciprocity,
suggesting that interdependence may not only exist but may also change over time in caregiver/care recipient relationships (Perkins and Haley 2013). Thus, family QOL and reciprocity also support the importance of the recurring theme of interconnectivity with others as being vitally important in QOL, as previously highlighted. Families of people with autism can have deeply intertwined lives across their lifespans to a level that other families could not begin to imagine.

Promoting a contented quality of life in adults aging with autism and their family caregivers

The remainder of this chapter briefly reviews what is known about QOL outcomes for adults aging with autism and their family caregivers. However, more importantly, it primarily focuses on what readers of this book should be cognizant of when supporting individuals with autism and their caregivers. The goal is to help enhance successful aging and promote a contented QOL. I propose that a contented QOL assures that overall a person is happy with their life’s relationships, activities, and living environment, and that the person has a life with meaning and purpose.

What do we currently know about the quality of life of aging adults with autism spectrum disorders?

Studies regarding older adults with intellectual and developmental disabilities have been undertaken for many years. More recently, there has been growing concern that the knowledge and training received by healthcare professionals largely ignores the field of disabilities and, in particular, the population of those aging adults with intellectual disabilities (Perkins and Moran 2010). This concern is also applicable to support workers who may receive little training on specific issues when aging with a lifelong disability.

Most existing aging research has focused predominantly on people with specific conditions such as Down syndrome and cerebral palsy. Unfortunately, aging with autism has received far less attention. There are several reasons for this, including the difficulty in identifying older adults who have never been formally diagnosed, the diversity of population to be studied (e.g., individuals with autism who have severe intellectual disability through to having IQs in the gifted range), and the diversity in people with autism’s communicative and adaptive skills (Perkins and Berkman 2012). Though there have been reviews of the literature regarding studies focused on aging with autism including my own, there is still a relative paucity of research that has specifically targeted those aged 65+ years, that is, the youngest category of aging in the gerontology field (Perkins and Berkman 2012).

In my review of the current research in the field regarding aging with autism, I noted several general findings (see Perkins and Berkman 2012 for a full review). Briefly stated, life expectancy for people with autism is similar to that of the general
population but decreases for those who also have greater severity of intellectual disability (Shavelle and Strauss 1998; Shavelle, Strauss and Picket 2001). There is evidence to suggest that issues with mental illness (e.g., depression, anxiety) lessen with increasing age; however, their prevalence is still far higher than that of the general population (Stuart-Hamilton and Morgan 2011; Totsika et al. 2010). Autism-related restricted repetitive behaviors, for example strict adherence to rigid routines, become less frequent and less severe (Esbensen et al. 2009). Vocational/employment and residential outcomes are still likely to be in less inclusive environments, and feelings of social isolation have also been described (Howlin, Goode and Rutter 2004). Mothers, in particular, have been found to have a great influence upon the social outcomes of their adult children. Mothers who are successful and determined advocates, who promote more inclusive environments during their child's younger years, help to lay a firm foundation for better social (e.g., more friendships), vocational/employment (e.g., gaining competitive employment), and residential outcomes (e.g., independent living) in adulthood and beyond (Orsmond, Krauss and Seltzer 2004).

What do we know about caregiver quality of life?

Most research reports of caregivers of people with intellectual disability do not generally analyze results on the basis of an autism diagnosis in their care recipients, but more often by level of intellectual disability, adaptive behavior, or factors including the presence of challenging behaviors (Haley and Perkins 2004; Williamson and Perkins 2014). However, concerns and challenges, such as the adverse effect on family wealth due to disability-related expenses, reduced employment options for the caregiver, stress and burden with caregiving roles, coping with challenging behavior, and social isolation, are present in caregivers of adults with autism as much as, if not more than, some caregivers of adults with intellectual disability (see Williamson and Perkins 2014 for a full review).

Most studies regarding QOL outcomes for caregivers of people with autism have focused on children rather than adults. This is unsurprising due to the importance of early diagnosis and intervention during childhood, in the most critical period for development. Research on older caregivers and their adult children with autism is rare. The term caregiver itself is often applied broadly and can include family who reside with the care recipient or provide support for the care recipient but do not live with them. The extensive duration and long-term nature of caregiving for an adult child sets apart this type of caregiving research, as does the fact that the caregiver will be outlived by the adult child with autism or other developmental disability (Haley and Perkins 2004). Another factor is that the caregivers themselves are aging, as well as coping with the aging of their adult child with autism (Haley and Perkins 2004). This is a far different scenario than the more time-limited ‘traditional’ caregiving roles some people undertake for their older parents or spouses (Haley and Perkins 2004). An illustrative example of research of older caregivers of adults with autism who did not co-reside together found that they rated their circumstances more positively than
those caregivers who do co-reside (Kraus, Seltzer and Jacobson 2005). This suggests that continued co-residence, as both the caregiver and the individual with autism ages, is not a desirable outcome for some families.

Planning and promoting successful aging with autism

Without doubt there are challenges to increasing age, changes in health status and function, and changes to our plans for the future, our daily routines, our relationships, and so forth – so much so that aging is often considered an accumulation of losses (e.g., losses of function, friends, and family, and so forth). The ability to adapt and cope, grow, and move forward from life events, be they positive or negative, is undoubtedly important. Such experiences and changes may be particularly problematic for people with autism to adapt to, especially if such changes are unanticipated and undesirable. However, such experiences are a fundamental part of life, and as with people without autism, exposure to unanticipated changes in routines, living arrangements, and/or social relationships can actually lead to new opportunities, experiences, and relationships.

Successful adaptability to aging-imposed changes can be achieved with selection, optimization, and compensation (Baltes and Baltes 1990; Bureau of Labor Statistics 2014). The Standard Occupational Classification (SOC) model relies upon people to select their activities carefully on what they most enjoy, with less focus on things they do not, optimizing their time with these selected activities, and compensate for things they find difficult with assistive technologies or alternative ways to achieve the same ends (Bureau of Labor Statistics 2014). Individuals with autism have often had a lifetime of adapting to and coping with what was for them difficult and less-than-ideal environmental conditions, routines, and activities that were not well matched to their own preferences, talents, and interests. I would argue that selection, optimization, and compensation is already practiced by many people with autism and their caregivers; thus, the adaptability to aging is not another process.

After considering the foregoing, and returning back to Rowe and Kahn’s (1997) successful aging model, I believe readers will connect the relevance to individuals with autism and those who support them. Thus, elaboration on the three aspects of their model – 1) lowering the probability of disease and disease-related disability, 2) enhancing the likelihood of high cognitive and physical functional capacity, and 3) promoting active engagement with life – is warranted.

Lowering the probability of disease and disease-related disability

It is evident that lifelong health issues (e.g., epilepsy) and mental health (e.g., depression, anxiety, obsessive-compulsive disorder) can impact the aging process as well as undermine QOL. One issue is that lifelong pharmacological treatments can have undesirable side effects, and for some this may result in increasing the rate of bone mass loss. Everyone loses some bone mass with increasing age – this is called osteopenia.
However, some medicines to treat epilepsy can accelerate osteopenia to trigger the onset of osteoporosis (when bones become brittle and more likely to fracture). Careful attention to the number and purpose of medications, as well as regular medication reviews, should be advocated.

The onset of many diseases and conditions more prevalent in later life, including cancer, heart disease or stroke, chronic obstructive pulmonary disease, diabetes, and so forth, are linked to poor diet, lack of exercise, and poor lifestyle choices such as smoking and excessive alcohol consumption. The importance of good nutrition can also not be understated. However, this is of particular concern to people with autism who may have preferred a restricted range of food-and-drink choices to avoid the unpleasant perception of tastes and textures they may have experienced with certain foods and drinks. Nutritional supplements may have been needed across the lifespan already but will be even more important as a person ages. Dietary allergies and intolerances, such as to gluten or lactose, can increase, making certain food groups more difficult to digest.

The importance of avoiding or reducing stress is also crucial to well-being. Chronic stress can affect immune system functioning and also predispose people to poorer health over time. Coping with the modern stresses of life and having quality time is especially important to caregivers, who might become so wrapped up in their caregiving roles and responsibilities that they have difficulty maintaining social relationships and having ‘me’ time. Caregiver encouragement and support to maintain healthy lifestyle choices, exercise, and nutrition can be exponentially beneficial as the person with autism also has a good role model for having a healthy lifestyle.

**Promoting high cognitive and physical functional capacity**

The often-used adage in gerontology of ‘use it or lose it’ is critical to maintaining cognitive and physical fitness in the older years. Irrespective of whether an individual has lifelong intellectual and physical disability, the goal in successful aging is to maintain those functional capacities. Decline is inevitable, but the rate of decline can be altered to be more gradual.

As we age, we are likely to lose muscle mass (this is called sarcopenia). Together, osteopenia and sarcopenia can increase the likelihood of frailty developing in older adults, which can adversely impact all their daily activities, and mobility. People with autism, whether they are ambulatory or otherwise, benefit greatly from regular exercise, with walking being the best ‘all-rounder’. For those who are not mobile, passive and weight-bearing exercises can still be effective to maintain good muscle and bone health. Exercise is also beneficial to offset depression and anxiety, which are considerably more prevalent in people with autism.

There is a real tendency within certain societies to encourage a relaxation of effortful activity as a perceived benefit of aging – that we have earned the right to take it easy. Retirement can sometimes endorse and emphasize this perception as a just reward for one’s working life. However, this may have a detrimental effect. Those who
maintain their physical activity and curiosity for learning are those that maximize their chance of continuing to age well. Increasing inactivity mentally and physically causes mind and body alike to atrophy (i.e., use it or lose it) rather than maintaining vitality. Physical exercise and mentally stimulating activities are not likely to be any less rewarding or impactful for people with autism and should be strongly encouraged.

There are many physical processes that change with age, including the fact that the thresholds for perceiving certain stimuli can increase (Saxon, Etten and Perkins 2014). It is common knowledge that our senses of taste, touch, hearing, and smell can diminish in acuity somewhat with increasing age. This has obvious implications for people with autism who have had lifelong issues with hypersensitivities of their sensory systems. These sensitivities can impact perception of touch, visual stimuli (e.g., fluorescent lighting), sounds, tastes, odor, and perceptions of pain. Indeed, aging may bring a time of greater tolerance to stimuli and environments that were previously very aversive to the person with autism (Perkins and Berkman 2012).

These changes can give rise to intriguing practical implications. Some individuals with autism may learn to tolerate a greater range of foods than in their younger years. Some may be able to tolerate noisier environments such as malls and restaurants. Some individuals may better tolerate being in closer proximity to other people and be able to attend concerts, sports venues, and other community events. Some older adults with autism may become more tactile with showing physical affection such as hand-holding and hugs. For these reasons, I believe there is a huge potential for further growth and development for people with autism, at a time when we often think the reverse is happening. Gerontologists’ adage of ‘use it or lose it’ reflects the maintenance of previously held skills, but there is a real opportunity for new skill building when previously undesirable stimuli no longer engender the same behavioral reactions, such as defensiveness, and can open new opportunities for activities and experiences that are truly life-enriching (Perkins and Berkman 2012).

**Promoting active engagement with life**

The previous goals of successful aging were to take responsibility to avoid disease and disease-related disability as much as possible, and maintain physical and mental vitality, but to what end? These activities can individually be self-satisfying but together greatly assist in our ability to remain actively engaged with life. Rowe and Kahn (1997) emphasized that the two most important forms of active engagement are interpersonal relationships and productive activity.

*Interpersonal relationships* serve an intrinsic function in and of themselves as individuals take pleasure in another’s company. Furthermore, social relationships are often perpetuated by participation in activities and social events that can take place within each other’s homes, the surrounding community, and in other geographical locales for special events and vacations. The rising popularity of online communities and social networking applications, such as Facebook, can provide a meaningful alternative source of social support to people with autism and their caregivers
(Perkins and LaMartin 2012). Indeed, opportunities to meet and maintain relationships that are logistically difficult to sustain due to geographical distance or transportation issues have no such constraints in virtual communities (Perkins and LaMartin 2012).

Productive activity serves to give some meaning to our lives. The difference between those who languish in their older years versus those who remain vital and engaged is a desire to be of benefit to something greater than ourselves or having a purpose. Such undertakings can involve continuing work-like activities or having hobbies (old or new) that the person was unable to devote as much time to during their work/vocational years. For many people this is achieved by active volunteerism. Productive activity is important because it can help provide routine to the day, week, or so forth. It can give a sense of meaning and accomplishment when productive tasks are undertaken and completed (e.g., painting, jigsaws, and so forth).

There is an additional factor of Rowe and Kahn’s (1997) successful aging that others believe should also be incorporated — that of positive spirituality (Crowther et al. 2002). It is the case that whether one is formally linked to an organized religion or has their own spiritual philosophies, this also gives meaning and purpose to one’s life across the years and as one ages. Indeed, connection to a spiritual community can enhance opportunities for interpersonal relationships and productive activity in volunteerism to one’s church. What has been most heartening is that many spiritual communities are becoming much more inclusive regarding outreach to people with autism and the accommodations that can be made to the church environment and services to increase the participation of people with autism within churches and other religious meeting places (Newman 2011).

So many of our younger years are somewhat routinized by work or vocational schedules and obligations. As these roles and demands diminish, their replacement with alternative or new activities helps to give structure to our daily lives as we age. Though some spontaneity is always welcome, a schedule that includes physical and mentally stimulating activities, promotes a healthy lifestyle, helps us remain connected with people we like and hobbies we enjoy, and gives us a sense of purpose will bring contentment to our daily lives. The focus should be on the activity, not whether it takes place within an agency serving people with disabilities, an agency serving older adults, or a community/leisure provider. Fundamentally, there should be a match between the activities enjoyed first and foremost, until the right fit for the person undertaking the activity is achieved. There is no reason that people with autism should have to expect anything less.

**Toward the future**

The common media often talks about the rise in autism. Regardless of whether there is a true rise in the prevalence of autism spectrum disorders for reasons as yet unknown, or the increase is due to better screening and earlier diagnosis, the fact remains that there is greater public awareness regarding autism spectrum disorders. Many questions
remain as yet unanswered, such as what causes autism and what can be done to reduce the risk of autism, prompting a very active research agenda in these areas. However, acceptance and advocacy of autism as part of the human spectrum of neurodiversity is fiercely promoted by self-advocates with autism. What is a fact is that there is a considerable population of people living and aging with autism. They will need the consideration of support workers, service designers and planners, and policymakers to ensure they too will be able to age successfully. Awareness of their needs also needs promotion to ensure they are not overlooked by the research community, provider agencies, and the public at large. There is a real danger that many families will not be identified or prioritized for support, even though they may have already provided a lifetime of support to their adult child with autism.

I acknowledge that the support available to people with autism and their family caregivers differs greatly worldwide. What is noticeable is that there are common trends emerging to promote greater self-determination in regards to post-secondary educational opportunities, vocational employment preparation, and focus on competitive employment that links a person with their skills, talents, and interests, rather than previous pigeonholing and confining occupational options such as sheltered workshops. In the realm of relationships, we are seeing people have more interpersonal relationships, and getting married. More people are starting to live independently, and move out of the family home at similar ages to their non-autistic peers.

There is a question of developmental preparedness and growth versus anticipated chronological timing for major life events. Just because a person is not prepared and wanting to assert their independence in their living situation, or develop skills for competitive employment choices in their twenties, there is no reason not to encourage them in the future, and revisit opportunities for growth. Knowledge regarding autism spectrum disorders is certainly more mainstream even compared with just 10 years ago. As public knowledge and interaction with children and adults with autism becomes more commonplace, so will awareness of the aging population of older adults with autism. Determining – and revisiting – life goals, formulating a plan, and discussing it with family caregivers should be a paramount endeavor to ensure smooth transitions. These transitions are from beyond school to working life and retirement, from beyond the family home to one’s own home, from beyond friends to the development of intimate relationships, from beyond social isolation to full community participation, to have, through adulthood and beyond, a contented quality of life and successful aging. This is not just desirable – it should be attainable for all.

References


