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# A Grassroots Community Dialogue on the Ethics of the Care of People with Autism and Their Families: The Stony Brook Guidelines

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**Abstract** The increased recognition and reported prevalence of autism spectrum disorders (ASD) combined with the associated societal and clinical impact call for a broad grassroots community-based dialogue on treatment related ethical and social issues. In these Stony Brook Guidelines, which were developed during a full year of community dialogue (2010–2011) with affected individuals, families, and professionals in the field, we identify and discuss topics of paramount concern to the ASD constituency: treatment goals and happiness, distributive justice, managing the desperate hopes for a cure, sibling responsibilities, intimacy and sex, diagnostic ethics, and research ethics. The members of the dialogue core committee included doctors, ethicists, administrators, social workers, ministers, disability experts, and many family members of individuals with autism who were especially engaged in community activities on behalf of their constituency, including siblings, parents, and grandparents. Our guidelines are not based on “top-down” imposition of professional expertise, but rather on a “bottom-up” grass roots attention to the voices of affected individuals and families speaking from experience. These guidelines can inform clinical practice, but they also are meaningful for the wider social conversation emerging over the treatment of individuals with ASD.

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The Committee members are listed in Acknowledgement section.

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## Introduction

The unique characteristics of autism spectrum disorders (ASD) call for broad reflection on a large number of ethical and social issues. In these Stony Brook Guidelines, which were developed during a full year (2010–2011) of community dialogue with affected individuals, families, and professionals in the field, we identified topics of paramount concern to the ASD constituency: treatment goals and happiness, distributive justice, managing the desperate hopes for a cure, sibling responsibilities, intimacy and sex, diagnostic ethics, and research ethics. Our guidelines are not based on “top-down” imposition of professional expertise, but rather on a “bottom-up” grass roots attention to the voices of affected individuals and families speaking from experience. Our guidelines are not evidence-based in the sense of a scientific assessment of prevailing opinions through a representative sample nationally or regionally. However, they represent the perspectives of our local community of affected individuals, families, and concerned professionals. These guidelines are thus limited in their significance and should be understood as the suggestive outgrowth of a particular local culture. We do not wish to elevate these guidelines to an authoritative status, or pretend that they have special significance vis-à-vis other local efforts of a similar type.

Identification of individuals with an ASD has increased dramatically from 30 years ago, when autism was considered rare (est. four per 10,000 children). Recent studies show that as many as one percent of children meet diagnostic criteria for an ASD. Once a person is diagnosed, optimal treatment requires many hours a week of structured behavioral and educational intervention, often at overwhelming expense to families. Most individuals with ASD have life-long difficulties that may require help and support, but services for adults with ASD are significantly less available than in early childhood. Clinical practice in the field of ASD must address an extreme range of disability from the severely intellectually impaired, often non-communicative and highly dependent child, to individuals who are highly intellectually developed but socially, and often emotionally, handicapped. Families are impacted by the demands of caring for their affected child and, not uncommonly, their affected children. Schools, healthcare services, communities, social and healthcare funding sources, and legislative bodies are trying to adapt to the needs of this growing population.

## Methodology

Guidelines for ethical care of individuals and families affected by autism are meaningful when grounded in a dialogue between those who are affected by ASD, their families, and caring professionals. Our method of “discourse ethics”

represents a shift away from heavy reliance on ethical theory and solitary reflection, and toward the epistemological priority of the voices of those immediately affected in daily life. It is a method that has been carefully defended philosophically and that returns ethics to the affected public world (Habermas 1993; Moody 1992; Post 2000). It allows caregivers and individuals with autism to bring to the fore issues and nuances that are easily missed by moral theories applied deductively “from above”. The model we followed is the influential Fairhill Guidelines on Ethics of the Care of People with Alzheimer Disease (Post and Whitehouse 1995) developed at Case Western Reserve University School of Medicine and the Cleveland Clinic, which became the baseline for two sets of national ethics guidelines established in dozens of similarly structured dialogues across Canada (Alzheimer’s Canada 1997) and the United States (Alzheimer’s Association US 2001, 2011).

From September of 2010 through June 2011, our committee of 17 professionals, nearly half of whom themselves had children or siblings with autism, convened monthly to reflect on ethical issues in autism in the form of a community dialogue (Post and Whitehouse 1995). The members of the committee were selected by a small leadership and drafting group of the Cody Center for Autism and Developmental Disabilities and the Center for Medical Humanities, Compassionate Care and Bioethics at Stony Brook University Medical Center ([www.stonybrook.edu/bioethics](http://www.stonybrook.edu/bioethics)). This committee included the family members (siblings, parents, and grandparents) of persons with autism, doctors, ethicists, administrators, social workers, ministers, disability experts, and those engaged in community support on behalf of this vulnerable constituency. The members of the dialogue were predominantly white, middle-class individuals and families as determined by our regional demographic. Topics were initially lightly suggested by the leadership core (Post, Pomeroy, Keirns, Isaacs, Dorn), but quickly the full committee adjusted these significantly to cover issues as they identified them and then established their relative priority. This prioritization was itself novel and highly instructive.

At committee meetings, special invited guests (family caregivers or higher functioning individuals with ASD) were invited in for each session to deepen our empathic sensibilities and understanding of their experiences related to the theme of the evening so as to ground our deliberations in the voices of affected individuals. Guests were drawn from the autism community at the recommendations of the committee’s membership. After an hour of dialogue with the guests, the committee discussed the topic at hand broadly for another 2 h in the light of personal and professional knowledge and experience. Because of the specific challenges with communication and social interaction caused by ASD, the dialogue participants with autism were more likely to represent the less cognitively impaired end of the autism spectrum.

Through reflection based on the personal and professional experiences of our membership, we sought to develop a set of ethical guidelines for clinicians and families. These guidelines are taken from careful notes that were developed and reviewed thematically after each monthly session by the core drafting authors (Post, Pomeroy, Keirns, Isaacs, Dorn), and distributed to committee members by email for responses. The guidelines as a whole were reviewed and approved by the committee at a substantive final meeting. They were then sent to each member, and were returned with written approval and consent for listing as an acknowledged contributor.

## Topic A: The Pursuit of Happiness

Asked to share long-term goals for their children, parents will almost invariably include a wish for their child to be happy. The way to achieve this is to show that an individual with an ASD is valued through unconditional love as manifested in acceptance, affirmation, attention, and tenderness. Any discussion of happiness or well-being in people with autism is complicated by the wide range of capabilities those with ASD possess, with some individuals highly functional and others much less so. But wherever any individual falls on the spectrum, their happiness or well-being, along with their security, is something that parents identified as a crucial goal of care. This is especially complicated for people with autism due to the emotional chaos that results from their diminished experience of the social world around them, and the social rejection and harassment that they often have to endure. It may, in fact, be more challenging for those at the milder end of the spectrum, who are more likely to attempt social interaction with strangers unsuccessfully, rather than to avoid it as those with lower functioning might.

According to our committee families, one source of recurrent unhappiness for some people with autism can be memories that do not fade over time. It was claimed that relatively high-functioning people with autism often seem to recall humiliation and hurtful behaviors with special intensity and painful persistence. We are not aware of this phenomenon being verified (Goddard et al. 2007). Perhaps the capacity for memorization that has been noted in many people with ASD prevents the process of forgetting and moving on to other things that is so critical to most people's coping with everyday life.

The theme of happiness is closely related to unconditional love. Happiness as a paramount goal of treatment and care inspired an award-winning documentary film, *Autism: The Musical*, which follows five children with autism, their parents, and an extraordinary acting coach who provides unconditional love as they mount a full-length original stage production, finding joy and community in the act of creating. Our Stony Brook School of Medicine students have engaged in bi-weekly modern dance (2014–2017) with people with autism and are able to create a community of palpable happiness and connection to the extent that the sense of inclusion in a shared humanity is overwhelmingly achieved judging by observed facial expressions of joy and behavioral adjustment, as has been reported in the autism movement therapy method (see Lara 2015).

## General Guidelines and Discussion

### *Guideline 1: Acknowledge that Individuals with Autism can Live Happy Lives and that this is a Central Goal in Their Care*

As one mother of a young boy with autism said to us, some individuals with autism may even be “happier than ‘normal’ or ‘neuro-typical’ people.” Without wanting to imply any generalizations, she continued, “We don’t know what is going on in the minds of those with severe autism who can’t communicate much with the outside

world. They may be very happy, or they may be miserable, or somewhere in between." Happiness can be readily apparent in the facial expression, tone of voice, and body language of those individuals with autism who are able to express themselves in this way, although not all can do so. As this same mother commented, "You could have seen it in his excited body movements and in his tone of voice when we went to see a model railroad exhibit last month. He was very happy!" People with severe autism still can assert will or desire, express a range of emotions, initiate social contact, express affection and warmth, interact with others, enjoy beauty and awe, and take delight in small gratifications to degrees that we may easily underestimate as onlookers.

*Guideline 2: Solitude Should be Accepted as a Place of Happiness for People with Autism, Atleast Within Limits*

We typically think of happiness or well-being in terms of prosocial engagement, and we fret when our children are not forming friendship networks. This anxiety can be carried too far. Historically and normatively, solitude has been deemed as contributory to happiness, especially in its more contemplative forms.

We heard from a 23-year-old young man who was diagnosed with Asperger's disorder at age 19 while in college. He described himself as always having been a good reader who found the key to happiness in learning from books. He felt like an outcast in high school, and never had a "bunch of friends". Much of his free time was wrapped up with his laptop and in playing video games, if not in reading. Computers served him as a limited and self-controlled social networking opportunity, and permitted an escape from the challenges and stresses of society. Obsession with "special interests" such as the history of World War II or China, may contribute to his isolation to the extent that they are perceived by those around him as strange. Receiving a diagnosis of Asperger's disorder was helpful for his self-acceptance and for his understanding of why his tendency to obsessive interests seemed unusual to people. With a diagnosis and subsequent life coaching, he became less of a "social failure", though socialization is always his big challenge. He continues to enjoy being alone and does not have many friends. Podcasts and videos are very satisfying for him. Now employed and "social as needed", he feels happy to be contributing effectively at work. But he still prefers to be alone and remains "mostly happy" as such.

Numerous parents in our core group commented that while they are anxious about solitude and social deficiencies because eventually their children will need to navigate society after they are gone, they recognize that "pulling" their children out of solitude into sociability requires a careful balance and an ongoing understanding that solitude has value. Many perfectly sociable individuals choose solitude, after all, and contribute to the world.

*Guideline 3: Encourage the Happiness that can be Found Through Contributing to the Lives of Others*

Considering happiness, the same young man with Asperger's disorder defined happiness as follows: "Being happy is being able to do what you are supposed to do

and function as part of a social setting even though you are not that sociable.” The opportunity and ability to contribute to society in some way is, he asserts, a universal key to happiness. He commented that he wants to be a college professor someday, although regrettably many people have told him that he can never fulfill this dream.

Another high-functioning individual with Asperger’s disorder, a young woman, experienced nothing but disdain in high school. She reported having been “treated as nothing, a retarded freak, with my personhood slowly taken away from me day by day. I was a shell by the end of high school.” She was “shut out, never a part of anything”. She became happier in college, in part because she was befriended by the sister of someone with autism who seemed to understand her and accept her. “And now,” she stated, “I don’t care what others think of me! It used to be that I could only be as happy as my peers permitted me to be, but all that has changed.” These days, she gets into the “flow” of cooking, which she enjoys, and uses this as a way of giving to others. She shares her wisdom by offering practical tips on how to navigate the experience of autism through her website, and offers her availability to speak to others like her. “Real happiness,” she asserted, “comes from accepting yourself for who you are, and making peace with your condition. And happiness is helping other people! It is knowing that I can really make a difference for others who are going through what I have gone through. It is about having a sense of purpose.”

The young man with Asperger’s disorder commented that he spends time on a website focused on ASD and occasionally contemplates giving advice to parents whose children are at the lower end of the autism spectrum. He feels that regardless of his being at the higher end, he still has special insights into how people with autism feel and is able to step into the world of the more severely affected because while their experience is more raw and intense, it is not altogether different from his own.

We heard often of the importance of support groups for parents. One mother spoke of how she opened up her home to sponsor a support group with other parents, and that this created a social space that was profoundly healing for them over the years. Most of the social dynamic in support groups involves helping the other people in the group with an understanding heart and practical advice, and it is in this self-giving that parents are “wounded healers” to other parents and their children.

*Guideline 4: Balance the Acceptance of People with Autism as they are with Efforts to Guide them Toward What they can Become*

Those caring for people along the autism spectrum are challenged to find the right balance between respecting the experience of a loved one with autism on its own terms and as it presents itself, and trying to encourage a loved one to achieve certain thresholds of social, emotional, and intellectual competency. One mother said, “We should always accept people with autism as they are, just as we should accept everyone as they are, but we can help them to be more comfortable in ‘normal’ society as much as they wish to be.”

For example, a child may be “stimming” (i.e., engaging in purposeless repetitive movements, sounds or speech due to unknown cause but which seems to provide positive stimulation or relief from stress) or engaged in a compulsive behavior of arranging objects in a precise way hour after hour. Why should we assume that such a child is not “happy” in their behavior? Why should we think that they must be pushed and pulled into “our” reality? To some extent we should not force our image of “normal” human experience on these unique individuals. On the other hand, these are children who must face the world in its intolerance of them, so they need to be as functional as possible in order to survive and cope. Parents and professionals try to do all they can to modify dysfunctional behavior and normalize the lives of these children, and often with astonishing success. Yet, it is possible to push and pull a child too aggressively and to fail to accept them as they are.

We can offer no universal recommendation other than to state that while leaning toward normalization, the innate happiness of the child can also be respected. We can affirm the person as he or she is while also removing obstacles to growth and providing opportunities for experiences that they would otherwise never seek. As one mother stated, “My son has trouble naming and explaining his emotions, but no trouble expressing them! His expressions are often not age-appropriate, or appropriate to the situation, but neither are they subtle. They may be happier than most just being alone, but a lot of introverted people can be happy in solitude as well...I learned a long time ago not to be embarrassed by my son’s behavior. Join in the laughter! Join in the dance! Why must we all be so serious?”

*Guideline 5: Physicians Should be Supportive of, and Open-Minded to, What only Parents can know About the Environmental, Social and Emotional Interventions that Seem to Help Their Child*

One mother wrote, “I try not to change his schedule without warning. He is much more flexible than he used to be, but he still has trouble making quick adjustments. I provide ear protection when he has to be in a noisy environment, since his hearing is very sensitive to certain frequencies. I put black-out curtains in his room because he can’t sleep with light coming in the cracks around the door. I often leave parties and larger gatherings that he is also attending earlier than I would really like to, because he has trouble tolerating the social strain. If we go camping we have to drive a vehicle in which my son can sleep with light and sound blocked out. A tent doesn’t do it for him. He also can’t sleep near people who snore, including his father...My son is 24 years old, and so we have had a lot of practice.” Another mother told us, “My son went through auditory integration training to help desensitize him to the frequencies of sound that hurt his ears. Some people with autism or ADHD wear colored lenses over their eyes to block out the frequencies of light that cause them problems. My son shaves the hair off parts of his body that his clothes tend to rub to lessen the irritation. With practice, people can improve their skills in reading facial expressions and body language, and can learn to moderate their emotional expression, but this takes a lot of time and patience.”

There is no substitute for the detailed personal knowledge that a loving parent gains through the experience of caring for a child.

***Guideline 6: We must Collectively Create Loving and Accepting Environments Devoid of the Bullying and Harassment that Destroy Happiness and Well-Being, and that Leave Deep Scars that are Difficult for Individuals with Autism to Erase Either from Memory or Emotion***

We heard from high-functioning individuals about how their self-acceptance was inhibited for years by social environments, especially high schools, in which they were ridiculed, rejected, dehumanized, and harassed. One mother stated, “When he had so much trouble in regular school I found a school that was specifically for children with autism, and it helped immensely. Because they understood his physical and emotional issues they could tailor an education program in which he was comfortable enough to learn. A big part of that comfort, I believe, came from knowing that he was accepted—even loved—just as he was. Now that he is an adult, he is in a program where that acceptance is present, and they work on social skills and other issues in a gentle and slow-paced way. He has made good progress there. He also enjoys his Faith and Light group, which is a faith-sharing group for people with disabilities. We are all in the same boat there, and the love and acceptance of the members *just as they are* is very attractive to him. Of course, being loved and accepted as we are is attractive to all of us, so people with autism are not so different in that respect, either.” She added, “Because people with autism often get more harassment because of their differences, their lives are more impacted. How would you feel if a group of your peers pushed you down on the floor of the school bathroom and started kicking you, for no other reason than the way you talk or act? That happened to my son in first grade. Similar things happen to people without autism, though. The results are the same.”

***Guideline 7: We can Increase Happiness by Respecting Freedom of Choice Within Limits***

Many individuals with autism are capable of making choices. Like the rest of us, their well-being is in part related to allowing and encouraging choices, which provides a sense of self-efficacy and agency. Yet most people with autism need frequent guidance and assistance, especially when they are making choices with major consequences. There are risks that come with making choices, and individuals with autism must learn from experience, just like we all do. One mother said, “My son still has trouble making decisions when given several options. He needs two options at a time to be able to decide. I make sure that people who work with him understand that, and don’t overwhelm him with too many options. Still, he does make choices, and really enjoys the ability to make choices. It does seem to impact his happiness.”

***Guideline 8: Clinicians Need to Direct Attention to the Ways in Which an Individual with Autism can Impact the Happiness of a Family System***

As one mother said to us, “We tried to find a sitter for my son now and then so we could have a little ‘normal’ time for the rest of the family. There are respite

programs which can help with this. We tried to do most of our family activities that included my (affected) son. This often meant that one parent would keep an eye on our son, and the other would stay with the girls. Sometimes we took two cars to an event so that one could leave early if our son became over-stimulated. The girls were sometimes embarrassed by his behavior, but that is often the case with normal brothers as well. I think that having a brother with autism made them more accepting of differences and more flexible than most people. Let's face it—the balance in our family is not the same as in families unaffected by autism. I am very blessed with a supportive husband. Many marriages don't survive an autistic child. I have twin daughters who are older than my son, and they shared my attention from day one, and always had each other. I think it has been hardest on my younger daughter (younger than my son). She had trouble understanding why I treated her brother differently than her, and why I held her to a higher standard in some ways."

A mother commented, "For me, the hardest part was (is) dealing with the ignorance of people who don't know about autism, and the things they do and say. I faced a lot of frustration, anger and fear. I have been on medication for depression more than once. It is easier now that my children are grown. My son is the only one left at home, and he is independent enough to leave alone for a few days at a time. I just call daily to check on him. Now we are looking for housing for him, which will be another long road. Right now there is no urgent need to get him out of the house, but we do worry about what will happen to him if both of us die suddenly. We have a will, and have named a guardian for him, but it is still a worry."

*Guideline 9: The Selective and Focused Use of Psychotropic Medications can be Helpful, but must be Carefully Assessed with Goals in Mind*

As a mother presented to us, "I think that parents can tell when their child is happy or unhappy, no matter how little there is in the way of communication ability. Finding out what affects the child's happiness, either positively or negatively, is a life-long process. Sometimes it demands a long process of trial and error. Other times we get a sudden flash of intuition. Sometimes it requires help from professionals, even necessitating the use of various medications. My son is now 24 years old. I have a much better idea of what influences his happiness than I did 10 years ago, but there are areas that are still a mystery to me. I suspect there always will be."

Psychiatric medications targeted on behavioral/emotional difficulties due to an associated disorder (e.g., anxiety, ADHD, mood disorder) can be very helpful. This is one area where expert clinicians can make an important contribution to the happiness of people with autism and, indirectly, to that of their families. Yet presently, social, relational, and emotional interventions remain most central in creating a world in which an individual with autism is less likely to manifest behavioral problems, for the causes of these problems lie as much in this domain as in the brain itself, and perhaps even more so. It is important that use of pharmacologic compounds not distract attention from social and environmental causes of behavioral and mood issues, for these causes can often be ameliorated or

even eradicated. Adverse consequences of powerful medications can be significant, especially in young children, and over-medication should be avoided.

## **Topic B: Hope and Treatments**

Hope has been described as the passion for the possible. How does the clinician address the hope that individuals and families have for a cure for autism? Families often will be willing to “try anything” in their desperation. In general, a clinician should cultivate hope without being unrealistic or neglecting to facilitate the acceptance of limitations. Small developmental gains should be acknowledged, affirmed, and celebrated.

It is generally agreed that there is no proven biomedical treatment or cure for autism and that the disorder continues to affect most individuals, to highly variable degrees, throughout their lifetime. However, there are numerous types of interventions that are reported to enhance the level of functioning or improve outcomes. Furthermore, treatments are often applied with a goal of addressing common associated features of autism such as emotional and behavioral disorders, sleep or eating problems, attention or focusing deficits, abnormalities in sensory experience, movement disorders, and hyperactivity, rather than the core symptoms of autism. Treatment planners also have to consider environmental factors such as class placement, teacher and parent skills, and adaptation to community expectations.

Biological treatments may ameliorate certain symptoms, but do not affect the core diagnostic features. Many of the pharmacologic treatments used in mainstream clinical care are “off-label”, involving the application of compounds approved for the treatment of other conditions, but that might plausibly be beneficial to people with autism. Some “off-label” use may be supported by research evidence, but usually is not, in part because so few trials are done in children. Thus, many concerned parents turn to Complementary and Alternative Medicine (CAM), and may place equal hopes there as well. Many families will try CAM therapies that have not been studied under rigorous scientific standards, but then again, many mainstream treatments have not been empirically validated either. Parents are confronted by a plethora of therapeutic claims. We strongly recommend that they share CAM options they are considering or using with all of their child’s medical providers, conventional and complementary. Generally these interventions are stated to be of no harm, but others may have significant risks.

## **General Guidelines and Discussion**

### *Guideline 1: Hope Should be Broadly Directed at Measures Known to Improve the Quality of Life of Individuals with Autism*

It is the moral task of clinicians to do what is in their power to prevent unnecessary despair and when possible, to offer hope.

Autism is a very complex condition or set of conditions and remains incurable. It is not merely an alternative pattern of thinking or unique personality. Given the complexity of autism, present scientific knowledge suggests that we can hope for a cure or more substantially effective interventions, but recognize that this is probably a long way off. Clinicians and families need to reflect together on the importance of tempering hope with patience. A focus should be placed on social-behavioral interventions, enhancing communication skills, symptomatic relief, and promoting the social acceptance of people with autism. (It must also be noted that there are those individuals, most likely in the Asperger group, who advocate for better treatment and services but who do not feel that they need a “cure” or the discovery of a gene that could allow pre-implantation genetic diagnosis and the discarding of “tainted” embryos.)

At present there is little evidence of the superiority of biomedical interventions in the early treatment of most children diagnosed with autism. The most effective early interventions are highly intensive structured educational and individualized behavioral programs that utilize techniques developed by behavioral psychologists. Unfortunately, without early diagnosis, these interventions are less effective, although they can still be beneficial, especially when coupled with schools that have progressive programs for students with autism and autism-like syndromes.

Most early intervention programs incorporate the proven theory and approaches of Applied Behavioral Analysis (ABA), which focuses on providing a structured environment for the child in order to maximize learning for language, play and social skills. Any of the well studied ABA-based programs show significant gains for at least fifty percent of the children—some ultimately attending schools with typical peers, although they are usually still distinguishable from these peers. Strategies based in alternative theories and approaches are also said to be effective but all tend to share the core characteristics of structured, developmentally appropriate, individualized, and intensive early interventional programming.

#### *Guideline 2: Planning for Treatment for Autism Ought to Assess, Evaluate, Articulate and Document Goals*

Decisions about treatment should be made with a clear understanding of goals, while balancing the positive and potential negative effects of specific interventions. Focusing on a cure for the condition remains a goal for research, but commonly the clinician is addressing quality of life concerns that impact the child’s development. Physicians should help parents arrive at reasonable treatment goals and expectations. Clinicians need to speak with families about patience and hope when it comes to early intervention programs which can be very beneficial, even as they are intensive, demanding on the families, and very time consuming. Clinicians need to be clear about what scientific studies show about the efficacy of available treatments, both behavioral and biomedical, and address patients’ hopes sensitively.

*Guideline 3: The Leading Edge of Medical Progress in Autism Treatment is Evidence-Based but is also Quite Improvisational, Requiring More Effort to Discourage Certain CAM Treatments as Families in Desperation will Try Almost Anything*

Parents are usually aware of the claims of many CAM treatments, and studies reveal that up to 75% of families try such treatments. Thus, clinicians must navigate the complex dynamics of parental hope, and their passion for the possible, in a way that is respectful and honest. Our dialogue group heard from parents who have tried many of the available CAM therapies, defending them in the name of hope, and who feel that some are relatively effective for pieces of the clinical picture. How is a clinician, committed to evidence-based treatments, best able to form an effective therapeutic relationship with parents who are committed to trying CAM treatments, even as they implement all standard behavioral and pharmacological approaches that are available through mainstream clinics?

The parents of a child with autism who are hoping desperately for improvement or cure are likely to want to experiment with dietary modifications (e.g., gluten free) and other interventions that they hear about. While there are established national standards in the treatment of autism that should be recommended and implemented, and while evidence-based treatments are to be emphasized, many families will become alienated from clinicians who categorically dismiss any or all CAM treatments for lack of clear evidence. We heard from parents who devoted themselves to doing as much informal research as they could on various CAM treatments, and who deemed themselves to be pioneers of treatments which may ultimately be accepted as part of standard medical care.

*Guideline 4: While Clinicians Should only Recommend Evidence-Based Treatments, they Need not Rush to Judgment with Regard to all CAM Treatments*

When providing treatment recommendations the clinician does need to be honest and frank, in a caring manner that helps rather than hurts trust. In the end, families will do what they want, but if communication remains open they may keep their clinicians informed about all treatment modalities. As a matter of professional duty, clinicians should indicate to families or to affected individuals that they believe that some CAM approaches are inappropriate, while some may, through formal study, be proven to provide benefit.

It is important to distinguish certain CAM treatments, such as dietetics, that can be deemed meaningful and healthy (although some are highly restrictive and needlessly frustrating), in contrast to more extreme CAM procedures. Some treatments, like yoga or music therapy, are relatively harmless in contrast to injecting a substance into the body. Other CAM treatments may be more questionable, but have an appeal especially for parents whose child will likely never live independently and whose needs are great. When a CAM treatment is potentially harmful, clinicians have an ethical and legal duty to inform parents of the nature of the risks they are assuming on their child's behalf. In the most extreme cases, involvement of child protection agencies may need to be considered.

Whether a treatment is mainstream or CAM, goals should be kept in close view, side-effects assessed, and harms avoided. Clinicians and families need to establish a

mutually respectful dialogue, and clinicians ought not to be dismissive of parents pursuing CAM treatments. However, CAM treatments should not displace recommended medical treatments.

*Guideline 5: Protective Guidance is Appropriate When the Diagnosed Individual is Making Treatment Choices that may be Harmful and/or Contrary to Best Interests*

Individual choice in using or declining biomedical treatments is a complex area in which freedom and persuasion must be weighed, especially when the degree of potential harm to the affected individual is high. With regard to medications intended to impact mood and behavior, the individual may wish to forego or stop treatment in the interests of quality of life. In psychiatric treatment this is not uncommon, for example, in patients who report that their cognitive skills, physiologic function and/or emotional range have been blunted. Yet there are many instances in which treatment refusal has had disastrous consequences. While autonomy should be respected, it is unacceptable to abandon individuals with autism to an autonomy that is not shaped and formed by experience or meaningful conversation. In some cases, persuasion is clearly justifiable. Nevertheless, the choice to discontinue medications, although often contrary to the best interests of the individual with autism, may sometimes improve quality of life. Those individuals who have been trained in coping and social skills from an early age may find success without pharmacologic therapies as adults, especially in cases of high-functioning autism spectrum disorders.

*Guideline 6: The Clinician Should Explain to Families that Given the Growing Numbers of Children Affected by Autism, and the Desperation of Many of Their Parents, Some Individuals will Try to Exploit this Financially Using So-Called Treatments that are of no Benefit or Even Potentially Harmful*

Our group debated intensely over the use of the word “charlatan”, a term clearly more comfortable for clinicians than for parents when considering CAM therapies. While we do not believe that the label “charlatan” should be loosely applied, clinicians are within their professional duties to speak of the potential for the economic exploitation of hope by predators who are primarily motivated by monetary gain.

Among the many CAM treatments that are unproven, often costly, and typically burdensome are: bleach therapy, transcranial magnetic stimulation, secretin injections, raw camel milk, chelation therapy, hyperbaric oxygen therapy, marijuana, gluten free and casein free diets, Lupron therapy, and various others.

### **Topic C: Supporting a Parental Love that Seeks Justice**

Justice means access to basic services necessary for human beings to maintain lives at some reasonable or adequate threshold of security and well-being. There is no single compelling “theory” of justice that people agree on. However, there is one

obvious and utterly compelling truth—we can recognize the faces of injustice. Often these are the faces of vulnerable people who lack the capacities needed to earn an adequate living, to live independently, to protect themselves from abuse, and to care for themselves. These people need forceful advocates, practiced in the skills of protecting and fighting for those they love. When it comes to individuals with autism, it is their parents who typically become their advocates, and thus we focus on them and on how they can be supported in a world of limited resources.

More work needs to be done to conceptualize and define the overall needs of the “autism community” in order to present a clearer case on its members behalf at the level of social justice and macro-allocation of resources, especially in a time of massive cutbacks in federal and state budgets. The big question of how to balance the rights of people with autism to a dignified life with the rights and needs of other groups is difficult for us to address. Yet we can speak with authority about the spirit of advocacy on the part of parents (and siblings) as we have heard this expressed.

## **General Guidelines and Discussion**

### *Guideline 1: Acknowledge, Affirm and Celebrate the Parent as Justice Advocate*

While we have no ideal theory of justice guiding how we address the needs of individuals with disability, what we *do* have are justice activists, who are unwilling to allow an identifiable needy constituency to slip beneath a reasonable threshold of security and well-being. In the case of the autistic community, many of these justice activists are parents whose love for their children drives them to advocate in education, health systems, social services, and across society to ensure that their loved ones as individuals and as a group receive the medical services, educational interventions, and other supports for housing and employment to allow them to participate meaningfully in society.

Without exception, every parent or sibling in our core dialogue group became an activist-of-a-sort. Their passion is crucial in the struggle for appropriate services for their own loved one. Yet, individuals with autism are not categorically different from any other vulnerable group such as people with mental illness, with quadriplegia, with severe learning disabilities, and the like. Often the justice gained for some through the tireless efforts of family activists, whose attention may be exclusively focused on their family member, will expand concentrically through new legislation and elevated public conscience so that other equally needy constituencies also benefit in the end.

### *Guideline 2: Support Parental Strategies for Fairness*

Parents, allies, and activists with autism, acting as “angels of rough justice”, must have wisdom, experience, and perseverance. We heard time and again that some parents can take better advantage than others of the legal “rights” of people with disabilities. They may be professionals who know the educational, healthcare, or social benefit systems in every detail—or have become professionals in these areas because advocating for their family members gave them inspiration and

experience—or they may have a certain assertive perseverance that eventually tires out these indifferent systems. A parent has to advocate strongly and will face every opposition—“expect challenge,” said one of our parent members. Those parents who succeed carve out new pathways and make the road easier for those who follow. One of our core group members, a sibling of a sister with autism, described how in the early 1970s, her mother advocated strenuously for her sibling, first to gain access to public school of any kind, then, five years later, for access to the general curriculum for the non-disabled when the special education curriculum had failed to challenge her. In the process, many others in their school district benefited, especially those with other disabilities, just by the fact that one girl with autism was included in regular classrooms.

#### *Guideline 3: Educate Less Informed Parents in Persistent Advocacy*

Given the experience of our group of parents, we think that every parent of a person with autism needs education in effective advocacy. They need to know about special education laws and rights, about insurance rights, and about all the domains of social support and government benefits. Parent activists themselves are the best ones to educate other parents and to widen the circle of knowledge. Clinical settings can nurture this process by putting parents in touch with parent support groups or advocacy networks. Some parents find these kinds of coordinators of services within social service or rehabilitation agencies, and other times have to become themselves the informed advocates, drawing together fragmented services of clinical, educational, and social service agencies.

#### *Guideline 4: Doctors and Other Professionals can Take up the Cause*

Physicians often serve as gatekeepers to developmental disabilities services, such as early intervention and special education, as well as adult services that support individuals with autism living in the community. Physicians not only assign diagnoses on the autism spectrum, but can also write treatment recommendations for schools and other entities that clarify the precise needs of an individual with autism, such as speech therapy, special education services, and behavioral therapy. The physician must become an advocate for his or her patients and their families, learn to write authoritative and compelling recommendations, and even refer parents to volunteer activist mentors. Such activities, of course, take time and are not compensated. Often, specialist physicians and centers for autism and developmental disorders or chronic care management offer patients and families these services. A primary pediatrician may suspect or make a diagnosis, but since they treat fewer individuals on the spectrum or with complex medical, educational, and rehabilitation needs, the primary physician rarely has detailed knowledge about the educational rights and systems that families will have to navigate. In particular, primary care physicians who regularly care for individuals with autism need to learn the specialized language that their recommendations need to contain in order to trigger legal obligations in the receiving educational institution, or at least

understand that this is part of what the specialist centers provide so that over time they can take over this role as medical advocates.

*Guideline 5: The Life Cycles of Families, as well as Individuals with Autism, Need to be Respected in Considering the Appropriate Balance Between Individual, Family, and Social Responsibilities for People with Autism*

A particular challenge of the assumption that families will care for their disabled members is that families have their own life cycles. Asking the parents of children with autism to care for their children in their own homes to age 18 or 21 is parallel to the expectations and obligations of the parents of any child in our society. However, expecting families to provide life-long care for people with autism who are unable to become self-supporting or live independently places the family caregivers at financial risk, reduces their ability to save for retirement or illness, and creates the likelihood that agencies will have to scramble to provide housing and social services when parents eventually become ill, disabled, or pass away. One member of our core group is an internal medicine physician, and just in the past year has taken care of two mothers in their 60 and 70 s of adults with autism who requested early discharge from the hospital despite, in one case, a serious heart condition and the other, a new cancer diagnosis, because there was no one else available to care for their adult children with autism. Rather than planning for the eventual and predictable deaths of parents of old age, developmental disabilities agencies instead manage these deaths as a crisis, scrambling to provide housing and services that the parents provided well into their childrens' 40, 50 and sometimes 60 s.

Considering the social support systems, E.K., an adult with autism, provides an example of the process. She became eligible for SSI (Supplemental Security Income) after college because her autism made her “unable to engage in substantial gainful employment”, the Social Security standard for disability, and her SSI eligibility conferred automatic eligibility for Medicaid. Because she lives in a state that provides relatively generous social services, she has also been able to live in a housing project for the elderly and disabled in which she pays a fixed percentage of her income for rent, and receives counseling and job coaching that enable her to work part-time. To someone such as E.K., whose independence and autonomy are critically important to the quality of her life, social service budget cuts could lead to the loss of her community supports and subsidized housing. She would risk either homelessness or a form of institutional care that would cost the state much more than her community services. Despite the reduced costs of community as opposed to institutional placements, there is so little new money allocated to place adults on Medicaid-funded waiver services that support community living, including housing, life skills training, and vocational support, that waiting lists in certain parts of the country have grown to several years for basic supports and up to twenty years for housing.

For families whose children are lower functioning on the autism spectrum, community supports and housing are even more costly because many such individuals require 24-h supervision, generally in staffed group homes. One of the

core group members, who had been successful in obtaining some funding toward community supports for her young adult son, was told that funding for a residential program for him is out of the question, given the current budget crisis. Although no regulations explicitly state this, the agency responsible for developmental disabilities has determined that unless there is a compelling need, such as a behavioral crisis or the incapacity of the parents, adults under the age of 40 will not have priority for residential funding. Consequently, the core member and her husband are funding the costs of his residential program entirely even though they are themselves of retirement age.

Perhaps more than ever, advocacy matters today, and it matters continuously. Are we seeing a reversal in the hard-won gains that have made the lives of individuals with autism and their families so much better?

*Guideline 6: It is Imperative to Serve as Patient and Family Advocates in Insurance Justice*

Insurance justice involves advocacy as well. When the diagnosis is autism, health insurance covers the basics of care that would be covered for anyone else: doctor visits, specialists, pharmaceuticals, and the like. However, highly structured, reliable evaluations and treatments for autism require multidisciplinary intervention by specialists from non-medical fields. For example, the tests typically provided by psychologists to diagnose autism, support and apply for special education needs, or establish eligibility for other services (e.g., Autism Diagnostic Observation Scale (ADOS), Vineland Scale of Adaptive Behavior as well as other measures of cognitive ability and processing), are rarely covered adequately by private health insurers. Nor do health insurers reimburse for structured educational and psychological interventions, including applied behavior analysis (ABA)—among the only treatments that have proven efficacious in treating children and adults with autism. There has been a great effort by parents and advocacy organizations to effect health insurance reform legislation, and there has been some expansion of and mandated coverage in 27 states to date (including in New York), but this remains sporadic and incomplete.

Ultimately, treatment and access to care for individuals with an ASD should not be a chance consequence of geography, local politics, community resources, health insurance, birth, or the ability of parents to advocate effectively, though this set of circumstances is hardly unique to autism. The concern raised by our group members that is specific to autism is the window of opportunity for early interventions that might substantially improve intellectual, social, and emotional functioning across a lifetime. A sense and practice of fairness needs to be developed such that all children with disabilities are provided with services appropriate to their need, with an understanding that the autism community should consider joining with larger movements in advocating for access to educational and medical services. This requires the ability to establish reliable measures of severity of disability and an appropriate range of services that would address each individual's needs. Setting mandates for evaluation and service is obviously a contentious issue but such a model could begin to address the need for fairness as well as justice. Ideally, parents

would not need to be advocating so intensively for their own child's needs if they were assured that services were provided on a reasoned and logical basis across all settings.

To reach these goals our group recommends a much fuller listing and description of evidence-based medical requirements for evaluation and treatment of individuals with autism. To establish a fair and measurable system would be complex. An imperfect but fairer service model has been developed in the Early Intervention (zero-three years) Assessment and Treatment programs in New York state. This program does not employ diagnosis-driven interventions (except in some regions for Autism) but assesses five areas of development (speech, cognition, sensory, motor, emotional/behavioral), establishing degree of delay in development of each functional area and allowing specialists to treat those delays which are of clear significance. Without further discussion it can be seen that there could be a structured model for assessment and treatment of autism that incorporates measurable function and defined goals but will have to adapt to great variation in clinical presentation and outcome. Equally, such a model would have to evaluate need across a community with regard to costs and resources and has the potential for difficult decisions in relation to where to place resources. For example, some might argue paradoxically that programs need to be more intense for children who have characteristics that might predict better outcome, as is done in fields like stroke rehabilitation. We need to define the concrete treatment needs of this population as well as how to most efficiently and most effectively provide the services required to meet them. Clearer standards are needed to be explicitly and fully stated across the spectrum and the life span.

#### *Guideline 7: Professionals Need to Advocate for Justice in the Legal System*

A number of our core group expressed a need to discuss the issues for individuals with ASD in the institutional justice system of the law. For those working in clinical service, most will be aware of young adults who come into contact with the law because of poor social awareness and judgment, social and communication deficits, association with and exploitation by inappropriate peers, potentially dangerous public emotional outbursts, inappropriate behaviors driven by their internal preoccupations (e.g., impersonating railway employee to gain access to his fixation on trains), or highly inappropriate sexual behavior due to naiveté or inability to relate appropriately. The community reaction is highly variable but there is a need to educate all within the legal system about this group of disorders. The role of the clinician is commonly to provide this education, to strongly advocate for treatment (not incarceration), and to establish that the behaviors presented are features of a clinical disorder. One difficulty that commonly arises, because of the nature of the individual's presentation, is the belief of some members of the legal system that even if he or she does have an ASD that this does not excuse their actions nor exclude facing the consequences. Community education is needed, including for police.

## Topic D: Caring for Siblings

Am I my brother's or sister's keeper? Siblings and the role they play within the family have implications for individuals with ASD throughout the life-span. There are numerous responses that unaffected siblings manifest ranging from withdrawal (e.g., resentment, indifference) to engagement (e.g., nurturing, supportive). These responses are as influenced by such factors as gender, resilience, intellectual abilities, birth order, family structure and stability (divorce, remarriage, other siblings or half-siblings), as well as individual characteristics, including temperament and possibly shared ASD characteristics between siblings (the broader autism phenotype).

Some typically-developing brothers and sisters develop close connections with their siblings with autism; some withdraw as adults and have little contact, and most face a range of emotions from protective and caring to frustrated, angry, sad, or bitter. As it is, all too many families are on their own socially and emotionally with a child with autism. Many siblings don't know how to help, and are unclear about what constitutes harassment. Later in life, many siblings are again on their own when their parents die and they are suddenly faced with guardianship of a sibling whom they may barely know, particularly if they never developed a close relationship.

Our guests at this session were four sisters, three reporting on their relationships with sisters, and one with a brother. We also had a mother reporting on the relationship between her two sons. All of these relationships reflected the engaged, caring and compassionate sibling, though all had also experienced frustration and ambivalence at times. Our sibling reporters ranged in age from 19 to 43, with siblings from 17 to 45, so they reflected a range of life stages. Our guests were reflective, responsible and calm; they also had enduring close relationships with their sibling from early childhood. This perhaps remarkable group of siblings had sometimes adjusted their lives to not only meet some of their sibling's needs, but also to develop skills and careers that could result in a positive influence on the needs of individuals with ASD. However, all had become frustrated at times, and most reported periods of reduced involvement with their sibling—e.g., during adolescence and early college years, with a return to a sense of individual responsibility as they established their careers and families.

Our guests for this session were siblings of an individual with ASD with a broad age range and severity of disability. Each of the guests had positive experiences with their sibling and was very involved with their needs. Thematically, they reported that they served as protectors, that they often sorted people according to their attitudes toward their autistic siblings, and that they grew and were transformed in clearly prosocial and benevolent directions on the basis of their relationships with and concern for their siblings. This translated into lives of elevated purpose, demonstrating that their social connectedness with their siblings was significant to them at deep levels.

## General Guidelines and Discussion

### *Guideline 1: Affirm Those Siblings Who Take on the Role of Protector*

B.L. is a 27-year-old woman who works with autistic individuals in Manhattan. As a sibling she feels she has always been her sister's protector. Her sister is eight years younger and diagnosed with Asperger's disorder. "This world is not very tolerant" of her sister, who is awkward and sometimes elicits angry taunts. "In frustration," says B. L., "I stand up for my sister. I try not to totally flip out on people."

C.K., a member of our core group, spoke of her sister, age 44, who from childhood was uninterested in other people and nonverbal until she was five or six. In 1972, she was precluded from enrolling in kindergarten. A year later, due to the then new U.S. Rehabilitation Act of 1973 (section 504 required reasonable accommodation in federally-subsidized education), this changed. The legislation was later expanded by the Education of All Handicapped Children Act of 1975, requiring a free and appropriate education for children with disabilities.

With a high IQ, C.K.'s sister was eventually mainstreamed, attending regular and then advanced classes. C.K. described herself as a protector and translator, helping her sister to understand other people's actions and perceptions.

Family experiences may lead individuals to seek careers in special education, social work, medicine, or disability studies. Others may actively avoid reminders in their professional life of the struggles and challenges they and their families have faced. Support for individuals and families, both specific to the immediate needs of children and adults with autism, and broader approaches to stress management, respite care, support groups, and counseling may help individuals and families increase their own resilience and support life-long bonds of mutual appreciation.

### *Guideline 2: Value the Sibling Role as a Source of Social Connectedness*

B. L. told us of her sister's loneliness. She sits at the computer and uses it as "her only social outlet". She tried college, but left. She experienced terrible bullying in high school, and this did a great deal of emotional damage. She tends to sit and stew about these negative experiences. B. L. tries to move her sister past these memories, but she is still afraid to try many things, and this keeps her isolated. B. L. nonetheless tries to draw her sister out—saying she serves as her "activities coordinator"—planning outings and get-togethers so her sister won't always be alone.

S., the 21 year old sister of a 19 year old boy with autism, described him as agreeable and easy, as her "best friend", and added that half of her own friends are on the autism spectrum. Brother and sister share a passion for cross-country running, practicing daily and competing together. According to S., while her grandmother does not encourage her to spend so much time with her brother, and while her father seems to be embarrassed by him, when in public, "I connect him with others socially." S.'s younger sister, however, does not share this close bond with their brother.

P. is a year older than her 33-year-old sister, who was her childhood playmate. She could not speak, but “we were close and connected, and we could communicate by eye.” As they grew up, P.’s sister went to a special school. The two sisters had completely different social worlds, and in high school one lived with their mother and the other with their father. P. then went away to college. But now they have reconnected, especially as P. became a disabilities researcher. In this case, two siblings were close early in life, drifted apart due to circumstances, and have reconnected in adulthood. P.’s sister is now able to use augmentative communication devices such as one which “speaks” typed words, clearly an important advance in breaking the silence of disconnection.

#### *Guideline 3: The Role of Sibling as Future Caregiver Should be Viewed as Complex*

B.L. asked, “What will my role be when my parents are gone?” There are burdens, and B.L. asked, “How do I maintain a relationship without being overwhelmed? The bullying really closed her off and made my life as a sibling that much harder.” Her relationship with her sister remains “relatively good”, and “we are bonded”. S. stated “I always take D. with me.” Though she has been away at college, she is coming home to attend a local medical school in order to be around D. She envisions that she will always care for D as she grows older.

Since C.K.’s sister and parents are getting older, sibling responsibilities have started to enter into decisions such as taking a job, in part, for proximity to her sister. Financial planning for her sister has centered on how family members can assist while allowing her to maintain her independence. She works part-time and receives Supplemental Security Income (SSI), but also benefits from Medicaid, subsidized housing, and rehabilitation services. Those supports, combined with the social life she has within her church community, allow her to maintain independence, dignity, and self-determination. Conversations among her siblings, parents, and grandparents have focused on helping her with social supports, crisis management, and supplemental financial assistance. Of particular concern are issues of inheritance, establishment of supplemental needs trusts, and holding funds for her benefit. These are complicated financial and emotional issues that must be navigated carefully in order to preserve eligibility for government benefits as well as to respect her independence.

In contrast to some families, where there may not have been clear discussion and planning for future care of the sibling with autism, one of the members of our core group, the mother of a 23-year-old male, told the group that she and her husband had had detailed discussions about his future with their older son, who has elected to be his brother’s guardian when the parents can no longer serve in this role. The family has moved the young adult into a supported apartment community operated by a well-established social services agency. The agency provides case management services, life skills training, vocational placement, and an active social schedule. Their older son wants to continue to be involved in decision-making about his brother’s care as well as to see him regularly for golf, movies, and other activities, but he also wants to know that there are supports in place to handle day-to-day situations that may arise, as well as for providing assistance in the event of a crisis.

Families need to be encouraged to make clear plans for the care of the child with autism as parents age. It must not be assumed that a sibling can or should take on the full role of parents.

*Guideline 4: Affirm and Support Siblings Who Feel Called to Advocacy and Service*

B.L. said that being a sister of a young woman with autism provided her with a “calling” to work with the wider autistic community. She is an advocate on behalf of all people with autism. S. started studying autism in a research lab during her high school years and is now going on to medical school with an eye toward helping individuals with autism. C.K. is a physician known for her capacity to interact very sensitively with patients and colleagues in part due to her experiences with her sister. P. eventually became a specialist in disability studies, with a special focus on individuals with autism. She focused on disability issues as a graduate student. Many siblings do not experience this call to serve people that seems to derive in part from their experiences as the siblings of individuals with autism, but clearly this is one of the hidden gifts in the moral and vocational lives of some individuals as they transpose their self-giving into expanding concentric circles based on their sibling experiences.

*Guideline 5: We Should be Aware that Some Siblings Categorize People by Virtue of Their Attitudes Toward Autistic People*

All of our siblings commented that they have learned to judge the character and personality of other people by virtue of their attitudes toward individuals with autism. Classmates, teachers, parents, and others who react in horror or disdain do not remain friends or retain the unaffected siblings’ respect, nor do those who are simply indifferent. Those who respond with actual interest in, concern for, and interaction with the sibling with autism are those whom the siblings judge as trustworthy. Here we have a much deeper notion of friendship than is typically the case, one closer to the idea that your true friends are those who share your fundamental values and commitments and are willing to support you in them. When dating her future husband, C.K. recognized his patience and compassion with her sister as among his most admirable and rare qualities. The siblings also discussed the increase in general awareness of autism in the community over the past 40 years. When B.L.’s sister bumps into or offends someone, she can explain that she has autism and she didn’t mean it. P. spoke to us of her wisdom as a child: “People who do not treat my sister well would not treat me well, although I was forgiving of people who just did not care about her.”

*Guideline 6: It is Important that Clinicians Inquire About Siblings and Address Their Emotional Needs for Social Support, Support Groups, and Counseling*

Some siblings need, and can benefit from, formalized emotional support in the form of counseling or support groups, and these should be available to them. As a subtext, two siblings did mention that they sometimes felt as children that all the attention

from their parents was going to their siblings with autism, and that their own needs were invisible, ignored, or neglected. This is something that parents should be aware of, and many in fact are, but it can be difficult to give full attention to siblings when parents feel overwhelmed or exhausted. Some siblings do feel resentful, and this may contribute to negative behaviors. Even when it does not, parents may need to be creative in thinking about how to meet the needs of all their children, whether by drawing on extended family or other approaches. When developmentally appropriate for the siblings, parents may bring them into some conversations so they can understand the diagnosis, perhaps see their sibling's doctor or school, and even ask for their input. All of our siblings mentioned teasing and bullying, which the siblings are more likely to witness than parents. They may be able to provide information about what is happening that the child with autism cannot, offer suggestions about how to manage it, or offer details for school authorities who need evidence to intervene.

In many geographic regions there are sibling support groups for those who feel as if they are alone in coping with an autistic brother or sister. Such groups allow siblings to gain perspective and feel less isolated in their experience. A core group mother spoke of her children. In her family, one sibling is very kind and understanding while his older brother with Asperger syndrome can be aggressive, loud, and hard to handle. Her daughter attended a support group, and that worked well. It can be very difficult for siblings to handle the public "meltdowns" of their brother or sister with autism, and to cope with difficult behaviors at home, as these can be very intense and require focused parental attention. It is hard for a sibling to feel equally cared for by parents when an autistic brother or sister demands so much attention and engenders such anxiety and stress in parents. Three of the siblings in our group talked about feeling embarrassed by the behavior of their brother or sister with autism, and all in the same breath said they immediately felt guilty for feeling embarrassed. Parents, physicians, teachers, therapists, and, above all, the siblings themselves, need to recognize that all of these feelings are human and normal responses and that jealousy, frustration, anger, confusion, sadness, and other responses are natural. Support groups help siblings navigate all these emotions, including guilt over their resentment or sense of embarrassment. Sometimes siblings do need actual therapeutic services to handle pent-up emotions, both for their own adjustment, and because processing and managing their emotions will make them more likely to remain engaged in their siblings' lives rather than withdrawing as some other typically-developing siblings have done.

Clearly the quality of life of an individual with autism is going to be shaped and formed in part by the behavior and attitudes of their siblings. Particularly in the case of a family with a child with autism, the family dynamics need to be assessed as both a potential strength, as well as a possible source of stress for all family members. If it appears that some members have adapted well to the situation while others are struggling, family counseling may be indicated. Furthermore, it should be noted that nearly a quarter of first degree relatives of individuals with ASD have some characteristics of individuals on the spectrum and a (different) quarter of these relatives have evidence of depressive disorders.

It is important for clinicians to screen for such difficulties in relatives who appear to be in distress and not assume that the sibling (or parent) is only reacting to family stress. Physicians can help these families to face important decisions, such as residential placement for the adults with autism, as well as detailed planning for the future care and support of that adult, though this will frequently require legal advice on issues such as supplemental needs trust funds. This planning includes determining what responsibility the siblings will have in caring for and taking over decision-making regarding the sibling with autism.

## Topic E: Intimacy and Sex

It would be difficult to exaggerate the depth of pain, frustration and suffering our guests reported experiencing with regard to this basic human drive for connection, fulfillment, and satisfaction.

Closely related to happiness and quality of life for many individuals with autism are *intimacy* and *sexual relationships*. In the field of severe disabilities, this is a complex and controversial topic area, one that has a long and ongoing history in the context of negative eugenics—i.e., the forced use of birth control or the sterilization of individuals considered “unfit” for reproduction. While courts have in general affirmed the “right” to reproduce, the implications of this right for the parents of the individuals with autism, and for the children born who also need to be raised, are hardly sanguine. This tension between freedom and control in the intimate lives of individuals with autism is no simple matter, and allows no easy balance between competing values.

The capacity for individuals with autism to have close intimate relationships is often doubted due to their degree of social cognitive processing and communication challenges. These doubts have some validity, but with clear limits. With the introduction of the concept of the broader autism phenotype or, more recently, the autism spectrum, such assumptions about the romantic and sexual lives of individuals with an ASD have had to be re-evaluated. No longer can there be a neglect of this crucial component of their lives nor expectations that none will typically date, marry, or become parents.

## General Guidelines and Discussion

*Guideline 1: Intimacy is a Goal that, However Difficult, can be Achieved, Though not Universally, Usually with Extensive Counseling and Education*

We were struck by the self-awareness and the dismay of our guest presenters as they explained their frustrations with trying to form intimate relationships, their keen awareness of their isolation, and their sad resignation that intimate relationships are often almost impossible for them. It can often be difficult for people with autism to achieve intimacy because many lack the necessary social skills, empathy, or social awareness to enter into a relationship with a sexual component, since they may have difficulty initiating or maintaining social activity. For example, it is hard for people

with autism to be aware of the significance of tone of voice, inflection, body language, and facial expression. There are people with autism who are highly intelligent but are so lacking in emotional and social insight that the barriers to intimacy are experientially overwhelming.

We heard of a 17-year-old boy with autism who cannot accept rejection, and as a result, attempted suicide and does not want to go to school. Thus, it is vital that any cruel and adverse cultural elements of the contemporary school culture be actively monitored and reversed. The emotions surrounding love and rejection can be very difficult for this population. They seem to be easily traumatized by the difficulties in starting and maintaining such relationships, and will often retreat from further intimacy as a means of protecting themselves from possible pain if the relationship ends. (Incidentally, males with autism, in particular, can be misperceived as “stalkers” because they do not recognize the inappropriateness of focused pursuit, particularly after the object of that pursuit has indicated that she is not interested.)

The importance of providing help to people with autism regarding intimacy was highlighted by a mother who described her 21-year-old son as both attractive and social, but constantly feeling a profound loneliness because he cannot connect with others at a deep level. He goes out on dates but cannot experience a feeling of connection and fears that he will never meet a woman he “clicks” with. J.B., a young man with Asperger syndrome, spoke about how grateful he is to have a male roommate as a friend, but noted that he had simply given up on the idea of a girlfriend because over the years he experienced an inability to read social cues and interact consistently with expectations. Relationships “fizzle” because it is difficult for him to sustain the social interaction required for the relationship to develop. Jokes are difficult for him to understand, and that stands in the way. “I don’t find comedy funny—when people tell jokes or a lot of comedians. [Even] Seinfeld, the humor goes over my head. The things I find funny other folks find ‘off the wall.’ Not being able to have comedy makes it really, really tough. My thing is science—if I could find a real science geek lady, I would be set.”

Education and skill-building can often enhance the potential for intimacy, which is possible but difficult to achieve. The foundations for sexuality are social, and require insights into social mores, boundaries and personal space. Everyone with autism is a candidate for sexuality education and for relationship and intimacy education depending on their degree of disability and the nature of their behavioral and cognitive challenges. However, curricula designed specifically for people with autism and other developmental disabilities need to be developed in order to educate this population about intimacy and sex. It is important that schools and other venues serving those with autism access these materials in order to prepare these adolescents and young adults for the physical changes and emotions associated with normal sexual development and to optimize the goal of intimacy in so far as individuals with autism wish to pursue it. Some people with autism benefit from coaches and support groups in which they do role playing and discuss solutions.

*Guideline 2: Significant Cautions Regarding Reproduction and Parenthood Remain Evident for the “Best Interests” of Both Individuals with Autism and their Potential Children*

People with autism may think about parenting but realize that this could be difficult because of the genetic nature of autism and the significant chance that their children may also have autism. With some exceptions, adults with autism often lack the skills necessary to care for a child and to sustain the constant verbal and non-verbal communication involved in raising a child. As one young man with Asperger syndrome said to us, “I would like someday to get married, but don’t want kids because it would be so hard for me to be a father.”

A mother informed us that she knew her daughter was sexually active as a young adult. She had thought about having her daughter sterilized, but did not because this is such a controversial issue, given previous abuses leading to forced sterilization. The daughter, who had been prescribed oral contraceptives, became pregnant while in a post-secondary residential program. She and her boyfriend had decided to abandon birth control in order to have a child and form a family. Her parents encouraged relinquishing of the newborn for adoption, unsuccessfully. The daughter and her now live-in boyfriend both have autism, and have difficulty with housekeeping, paid employment, and parenting. The daughter is subject to behavioral meltdowns, including loud and hysterical screaming, and emotional chaos, and therefore she cannot be left alone for long periods with her child. The boyfriend tends to “leave” when this chaos erupts. Their son, who is now five, was diagnosed with Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS), which is a diagnosis within the Autism Spectrum. The daughter’s parents maintain an apartment for them within their own home and provide much of the financial and emotional support that this young family requires, including managing the education and therapy that their grandson requires. Although the school district provides parent training for the young parents, they receive only 2 h per month, which is inadequate to teach this impaired couple how to be effective parents to a child with a disability.

*Guideline 3: For Individuals with Autism, Consent to Sexual Activity is Often Ambiguous*

People with developmental disabilities, including autism, can require specific protection from sexual activity. They may not understand the meaning of “consent” to such activity. For individuals with autism who do not have intellectual disability, it is presumed that they can understand sexuality, sexual activity and the emotional and physical components of sexual activity including sexual intercourse. For those who have intellectual disability, particularly those with IQs of less than 70, ability to consent is determined by a formal evaluation process, although there are no objective standards by which someone is judged consenting or non-consenting. There are a number of instruments that can be used to help the evaluator, but the conclusions of the evaluation often depend on the individual professional and his or her advisors.

One mother was concerned with an agency that was overly prescriptive with regard to intimacy. She was determined to find sexuality education and counseling for her daughter, as well as the daughter's boyfriend, on her own, in an effort to permit both of them to become consenting, if possible. She has detected resistance from her daughter's agency about supporting this relationship. Because of this, she has been interviewing other agencies looking for one that is more forward thinking about the rights to intimate relationships for people with intellectual disability. Eventually, if it is appropriate, the mother, as well as the man's parents, would like to see the couple able to live together in a supervised setting that will permit and support their relationship. But finding placements can be very difficult.

*Guideline 2: We must Recognize the Vulnerability of People with Autism and Help them to Protect Themselves from Exploitation*

It is important to help people with autism build skills to deter exploitation or abuse in intimate relationships. Individuals with autism are vulnerable to poor treatment by others with dishonest intentions and, therefore, must be protected and supported. Lacking insight into the intentions of those around them, with limited capacity for enduring relationships and yet wanting to experience meaningful intimacy, the person with autism is easily exploited. As one young woman with autism told us, "Is it love or not love? That is confusing for us. We are never quite sure. We can be taken advantage of like a little child. It is hard for me to understand if a guy is respecting me or not, but I deserve to be respected and cared about. I'm glad I found the words to protect myself."

A mother testified that her daughter with Asperger syndrome was sexually assaulted in the eighth grade by several young men while riding on the school bus. She had no idea how to defend herself, and even lacked the words to say "no" and to call for help.

Many people with autism are naïve and unable to deter aggressors. They may not even recognize sexual abuse, or realize that they are receiving attention that could later turn into sexual advances. Those who care about them can hope to intervene effectively, but this can be very complex and challenging. Parents and others in authority need to provide clear direction to their children on the nature of sexual abuse, and about how they can alert an adult when they feel threatened sexually.

## Topic F: Diagnosis

The accurate diagnosis of ASD has important implications for service needs, communication, research, and thereby the ability to provide consistent and reliable information to families. Diagnosis is an important first stage in the relationship between parents and clinicians—a point when parents need the professional opinion of experts regarding diagnosis as well as the security of a clinical base from which they can obtain reliable information about implications of the diagnosis, treatment, and the potential for long-term professional support.

Diagnosis of a disorder on the autism spectrum can be difficult given the wide range of symptom severity and degree of associated cognitive impairment, the varied clinical presentation over a lifetime, and the fact that autism is a diagnosis that reflects characteristics of development before three years of age—requiring retrospective data for assessment when evaluating an older child, adolescent, or adult. Furthermore, autism has been associated with identifiable related or causative syndromes (e.g., Fragile-X Syndrome, Tuberous Sclerosis) and often has co-morbid clinical disorders (e.g., behavior disorder, anxiety, depression, sleep disorder, G-I disorder) that may require intervention or treatment independent of the core characteristics of autistic disorder. Diagnosis is therefore a multilayered task that may involve the skills of many different types of professionals.

The ethics of providing a diagnosis revolves around certain core principles, including truth telling, respect for hope, confidentiality, and a regard for autonomy. These principles must be balanced with the optimal long-term good of the affected individual and the family and the minimization of harms and burdens. In the final analysis, each case must be navigated on its own terms.

How does a clinician share a diagnosis of autism to an affected family and individual in a manner that is helpful, hopeful, and realistic? How is a plan of action best presented and discussed? Should generalists or specialists be making the final diagnosis? And how should the inevitable request by parents for prognostic clarification be handled?

## General Guidelines and Discussion

### *Guideline 1: Parental Concerns About Development Should Never be Trivialized*

Parents still report comments from pediatricians such as, “Well, he’s a boy and he will catch up,” or “No need to be a nervous mother.” Parents may have observed abnormalities over time, and comments such as these tend only to demoralize or outrage them. Generalist pediatricians do not need to be experts on autism, but they need to be able to make a preliminary assessment that leads to speedy referral to specialists based on a standardized pediatric assessment. To facilitate generalist assessment, simple screening tests such as a questionnaire given to parents can be used in the pediatric waiting room during appropriate well visits. For example, the M-CHAT, designed to identify potential ASD has been widely available and in use for several years.

### *Guideline 2: Pediatrician and Family Practitioners Need to be Well Informed About Autism and Keep up with New Developments*

We assert that the bar for knowledge about autism (and developmental disabilities) should be raised in pediatric training, beginning with medical school, and continuing in residencies and licensure exams. As one of our physician participants reported, in 2001 there was only a single multiple choice question about autism on her physician licensure exam. Psychology licensing exams are also weak in this regard. It does appear that the overall knowledge of autism among pediatricians may

be improving, yet much more can be done in regards to clinician education. This is also important for adult practitioners.

*Guideline 3: In Making the Diagnosis of Autism, we Advocate for an Ideal Two-Step Process*

An informed pediatrician or generalist should make an initial probable diagnosis, followed by the critically important referral to clinicians who are more knowledgeable in the area of autism. Ideally, this should be facilitated by an available community referral resource. The pediatrician should be knowledgeable about the resources in their community and make appropriate and timely referrals. If a community referral service is unavailable, a list of resources should be made available to families.

A definitive diagnosis can only be comprehensively developed if done by a group of experts. Those making the diagnosis should also discuss a treatment plan. Follow-up and treatment options can more easily be implemented in a specialized setting. In many communities, clinics and specialists are not available. In general, we believe that these settings should be available to every child and family across the United States, and that costs should be uniformly covered by private insurance or by public resources. It is vital that such a specialized setting be able to offer guidance on recommended and available professionals, possible entitlements, support groups, and other resources. Establishing intensive early intervention through proven approaches of structured psychological and educational programming should be the initial goal for the young child.

*Guideline 4: Disclosure of the Diagnosis to the Affected Individual is Dependent on Age and the Degree of Disability*

There is little room for sweeping generalization about diagnostic disclosure, and obviously very severely affected individuals will never understand or recognize their disability. Diagnosed children, especially teens, will have their individual perspectives on the diagnosis, depending on their degree of insight and self-concept. Sharing descriptions, key facts, written materials, examples and possible solutions at a level where the child or adolescent can understand information is essential, and, on the whole, much more important than immediately proceeding to labeling the disorder.

Because children with autism may be in their very early years when their parents obtain a diagnostic assessment, diagnostic disclosure is in large part made to parents. However, for the child who grows into adolescence or begins to recognize their own difficulties, *whether* the diagnosis should be explained to them, and if so, *when* and *how*, especially given the heterogeneity of cognitive capacity on the autism spectrum, should be handled case by case. Many older children and teens are also being diagnosed for the first time, and should be included in the diagnostic process to the extent possible.

*Guideline 5: Maintaining Confidentiality of Diagnosis is a Complex Matter and it is Clearly not an Absolute*

Parents and professionals are often concerned that early labeling could influence how others approach diagnosed individuals. Assumptions of functional limitation or diminished individuality could, they fear, impact on a child's outcome and future. However, while confidentiality is an important value, there are many anecdotal cases reported by parents who have explained what autism is like to the grade-school peers of the children, and have found that this helped the other children accept and support the child with autism, and possibly reduced bullying. Schoolmates can adjust and relate better to a child, as well as be more helpful, when they are informed about the diagnosis and nature of the disorder. In general, letting schoolmates know of the diagnosis can be a turning point for better acceptance, especially as stigma around autism subsides in our culture.

*Guideline 6: Parents and Siblings Should be an Active Part of a Clinical Team*

Diagnosis is not an end point in itself, but a starting point. In the process of giving a diagnosis, discussing possible outcomes, and considering potential interventions, it is important for clinicians to partner with parents and, whenever possible, siblings and the diagnosed children themselves. An emphasis on the continuous re-evaluation of treatment goals and evolving outcomes with parents and children is essential to good care. There was a time when a diagnosis of "autism" was considered a developmental death sentence, and physicians largely ignorant of the disorder tended to shy away from giving parents a clear diagnosis. Now, much can be done to ameliorate developmental deficits, especially if the diagnosis is made early. Such hope encourages truth-telling. If in earlier decades the diagnosis was typically poorly received and denied, nowadays many families have a strong sense of the likelihood of the diagnosis before they come into the doctor's office based on what they have observed and read. They often seek confirmation and clarification of where a child fits on the autism spectrum and in their lives as individuals and family members.

*Guideline 7: Definitive Statements About Prognosis are Rarely Appropriate at the Time of Diagnosis*

Both parents and affected individuals almost always want a prognosis. It is better to emphasize continuity of care and commitment rather than to try to predict an outcome. The range of outcomes can be described, but it is impossible to prognosticate in any individual case. The answer to the question, "Doctor, how will this develop?" is simply, "I do not know enough at this point." With outcomes so unpredictable, a compassionate response acknowledging this uncertainty is best, coupled with an affirmation of continuing assistance and active follow up.

## Topic G: Research Ethics and Emerging Treatments

Performing research with human subjects unable to provide their own informed consent remains controversial, as it should. Nevertheless, individuals with autism have a right to the benefits of research. Thus, proxy permission is valid for most types of research, although it can result in harms due in part to the enthusiasm of family members for experimental treatments that hold out any hope at all for a loved one. While we accept the validity of parental permission, except in cases of greater than minimal risk and no potential therapeutic benefit to the subject, we do so with the cautionary note that parents should be wary of exaggerated claims for therapeutic benefits and inadequate statements about potential risks and harms.

We clearly need to continue to do research on how to bring out the best in individuals with autism, recognizing their individual strengths and developing better ways of optimizing these. Given the biological complexity of autism, and the unlikely scenario of an immediate “cure”, social, relational and educational research is as vital as biological investigation, and has a greater potential to be directly beneficial. However, such investigation needs to follow ethical research guidelines. Though it appears less intrusive or potentially harmful than biologic studies, it does not preclude significant harm to an individual occurring in such research. For example, some children, due to study design, may be excluded from a positive intervention (the control group), and researchers must justify this. Parents must understand any risk related to such loss of treatment.

The varied perspectives and voices of clinicians, scientists, the families, and now, most provocatively, articulate individuals with a diagnosis of ASD, reveal very different concerns about research goals and methodology. At one extreme, some question whether a “cure” for autism should be sought and even be applied to individuals if found. Questions arise as to whether individuals with ASD, even if cognitively more able, can make informed decisions regarding inclusion in research, or if parents or guardians can make truly objective decisions regarding their dependant’s inclusion in research, especially when no specific benefit to the affected child or dependant is anticipated. Particular concerns are also expressed regarding too rapid a move from initial exploratory research investigations to mass community application of theory and/or intervention that is not warranted by the present data. This not only influences parents desperately seeking new treatments for change, but also typically has a financial and emotional cost for the families involved.

### General Guidelines and Discussion

*Guideline 1: There is a Need for Community Education About Research Procedures, Potential and Risks, and Why There Should be Such Rigorous External Review*

We were in general struck by the unawareness in the families of individuals with autism of regulations designed for the protection of human subjects, and we suggest that more education is needed to provide parents with information about why and

how these protective policies arose in the aftermath of abuses of research subjects that first came to public attention in the 1960s. But this may not be an easy or convincing undertaking, for the parents in our core group seem to find current regulations overwhelmingly complex and generally obstructive.

Research is essential to improving our understanding of and ability to treat autism. However, in discussion about the application of ethical oversight and apparent restrictions on clinical research through Institutional Review Board (IRB) review, there was significant frustration for a number of families with the degree of perceived limitations to furthering knowledge and understanding of ASD through research. A basic principle of ethical clinical research is that the quest for new knowledge should never take precedence over the welfare of the research subject. For this reason, no individual with autism should be subjected to greater than minimal risk in research that does not hold out the potential for direct benefits to the research subject. We should not place individuals with autism in harm's way solely to gain new knowledge about autism. All research on subjects with autism requires scrutiny by professionals, researchers, and lay persons on IRB review bodies.

There are adult individuals with autism who are sufficiently competent to give consent to research that will subject them to potential significant harms purely for altruistic reasons of contributing to knowledge, but no individual should ever be placed in this position on the basis of parental (or guardian) permission.

*Guideline 2: “Altruistic Harms” on the Basis of There Being only “Slightly Greater than Minimal Risk,” Should be Closely Examined*

In research that is greater than minimal risk, parents should ask themselves if there is a plausible potential benefit for their child, and if so, parental permission can be accepted; if not, parental permission should neither be given nor accepted. Even when there is potential benefit for the autistic research subject such that greater than minimal risk might be accepted on the basis of parental permission, we are concerned that so little attention has been given to what the limits on such risk should be. Much more needs to be said about the “maximal potential risk” that anyone with autism should be subjected to, even for the study of interventions that have a probability of direct therapeutic benefit to the research subject.

*Guideline 3: We Recommend that Parents be Cautious About “Off Label” Use of Medications that have no Empirical Verification in this Population, and in Addition, that may be Costly or have Adverse Side Effects*

We note that a great deal of untested and novel treatment occurs informally as clinicians (following their intuitions) use existing FDA-approved compounds “off label”. There are currently no restrictions regarding this practice but clinicians and/or researchers should have justifiable claims of potential gain and limited harm for their clinical subjects. Frequently, these intuitions have very little plausibility and lie outside the range of formal research policies and constraints.

We further caution that often business interests lie behind “off label” uses of compounds for autism, creating a major and growing new market for

pharmaceuticals, both traditional and alternative. The establishment of new markets is being aggressively pursued by pharmaceutical companies. Meanwhile some clinicians are making significant financial gain in prescribing off-label medications in addition to alternative treatments that are not under the purview of governmental supervision. Marketing plans for possible treatments are often in existence preceding any evidence of the claimed benefit. Children with autism have been exposed to numerous classes of psychotropic medications in small open-label studies that often reveal some justification for further examination of potential benefit; however, adequately large double-blind studies have commonly not been performed before the drug is used by some in clinical settings. In addition, experimental treatments that are approved by the FDA merely for early phase trials are sometimes presented as already approved for general clinical use.

## Conclusions

We hope that these guidelines will be useful for clinicians, families, policy makers, educators, and the wider community. The guidelines do not pretend to cover every issue that arises in the care of individuals with an ASD and their families. They do, however, present a thoughtful grass-roots perspective on a range of issues determined to be important by those affected.

As the numbers of individuals with autism increases, many families and policy makers must come to grips with the realities of such care. It is important to realize that a great deal can be done to enhance the lives of people with autism and of their families. We believe that human dignity requires us to pay special attention to the complex social and ethical questions pertaining to this vulnerable constituency. This is a time when compassionate respect, justice, good clinical ethics, and education are imperative. Our community dialogue guidelines are not intended to be the final word, but they do invite more systematic social scientific investigation going forward.

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