

Brief Report: Stony Brook Guidelines on the Ethics of the Care of People with Autism and Their Families

Stephen G. Post · John Pomeroy · Carla C. Keirns · Virginia Isaacs Cover · Michael Leverett Dorn · Louis Boroson · Florence Boroson · Anne Coulehan · Jack Coulehan · Kim Covell · Kim Kubasek · Elizabeth Luchsinger · Shana Nichols · James Parles · Linda Schreiber · Samara P. Tetenbaum · Rose Ann Walsh

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Abstract The increased prevalence of autism spectrum disorders (ASD), with associated societal and clinical impacts, calls for a broad community-based dialogue on treatment related ethical and social issues. The Stony Brook Guidelines, based on a community dialogue process with affected individuals, families and professionals, identify and discuss the following topics: treatment goals and happiness, distributive justice, managing the hopes for a cure, sibling responsibilities, intimacy and sex, diagnostic ethics, and research ethics. Our guidelines, based not on “top-down” imposition of professional expertise but rather on “bottom-up” grass roots attention to the voices of affected individuals and families speaking from experience, can inform clinical practice and are also meaningful for the wider social conversation emerging over the treatment of individuals with ASD.

Keywords Autism · Ethics · Clinical practice · Treatment · Social issues · Goals

Introduction

The societal challenges presented by autism spectrum disorders (ASD) call for reflection on a number of ethical issues. Guidelines for care of individuals and families affected by autism are needed, but to be meaningful such guidelines must be grounded in a dialogue among and between concerned professionals and those primarily affected. The Stony Brook Guidelines, developed after a yearlong series of dialogues with affected individuals, families, and professionals in the autism field, cover topics of paramount concern to the ASD constituency: treatment goals and happiness, distributive justice, managing the

S. G. Post (✉) · C. C. Keirns · M. L. Dorn · J. Coulehan
Center for Medical Humanities, Compassionate Care,
and Bioethics, Stony Brook University, HSC Level 3,
Rm 080, Stony Brook, NY, USA
e-mail: stephen.post@stonybrook.edu

J. Pomeroy
The Cody Center for Autism and Developmental Disabilities,
Stony Brook University, Stony Brook, NY, USA

V. I. Cover
Setauket, NY, USA

L. Boroson · F. Boroson
Port Jefferson Station, NY, USA

A. Coulehan
Stony Brook University Medical Center, Setauket, NY, USA

K. Covell
The Press News Group, Watermill, NY, USA

K. Kubasek
Developmental Disabilities Institute, Smithtown, NY, USA

E. Luchsinger
Mt. Sinai, NY, USA

S. Nichols · S. P. Tetenbaum
ASPIRE Center for Learning and Development,
Melville, NY, USA

J. Parles
Smithtown Pediatrics, Smithtown, NY, USA

L. Schreiber
Maryhaven Center for Hope, Port Jefferson, NY, USA

R. A. Walsh
Autism Speaks, Huntington, NY, USA

desperate hopes of a cure, sibling responsibilities, intimacy and sex, diagnostic ethics, and research ethics. Discourse ethics, our approach, returns ethics to the affected public world. It allows caregivers and individuals with autism to bring to the fore issues and nuances that are easily missed in moral theories applied deductively.

Methods

A committee of 17 professionals, nearly half of whom had children or siblings with autism, convened monthly from September 2010 through June 2011 to reflect on ethical issues in autism. The committee, selected by a small leadership group from the Cody Center and the Center for Medical Humanities, included doctors, ethicists, administrators, social workers, ministers and disability experts, along with family members of individuals with autism. Guests were also invited to join, including siblings and parents. The group included many well-known advocates, who, because of the demographics of the region they were largely white and middle-class.

Before each monthly session a schedule of possible discussion questions were drawn up by the leadership core and distributed amongst the committee members. At the session itself, these and additional questions were covered through dialogic conversation. Discussion leaders took their own notes and all sessions were audio recorded. The guidelines were then drafted from the notes by members of the leadership core and then shared with committee members by email for review and revision. At the conclusion of the monthly sessions, the guidelines as a whole were distributed and reviewed once again by the committee with suggestions integrated at a final meeting to which all committee members were invited to attend. The guidelines document was then sent to each member, and editorial responses were returned along with written approval and consent to be listed as a collaborative author.

Results

While the entire Stony Brook Guidelines document is available for download on the web (<http://stonybrook.edu/bioethics/stonybrookautismguidelines.pdf>), we wish to share a sampling of the findings from discussions of *Hope and Treatments*, *The Pursuit of Happiness*, and *Caring for Siblings* that also give a sense of their community focus.

Happiness

Any discussion of happiness and hopes for the future 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 identify as a crucial goal of care.

Individuals with Autism Can Live Happy Lives

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, as it presents itself, and trying to encourage a loved one to achieve certain thresholds of social, emotional and intellectual competency. Parents in our core group shared their anxiety about solitude and social deficiencies because eventually their children will need to navigate society after their parents are gone. This anxiety can be carried too far—historically and normatively solitude has been viewed as contributory to happiness, especially in its more contemplative forms. While solitude can be accepted as a place of happiness for people with autism, professionals and parents may also encourage the happiness that can be found through contributing to the lives of others.

We Can Increase Happiness by Respecting Freedom of Choice While Working Together to Create Loving and Accepting Environments, Devoid of Bullying and Harassment

There are risks that come with making choices, and individuals with autism must learn from experience, just like we all do. While many individuals with autism are capable of making choices, most people with autism need frequent guidance and assistance, especially when they are making choices with major consequences.

Hope and Treatments

Hope has been described as the passion for the possible. Finding 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, balancing the positive and potential negative effects of specific interventions, while at the same time acknowledging, even affirming and celebrating, small developmental gains.

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, 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.

Although “evidence-based” proof of therapeutic efficacy through the randomized control study is a gold standard in medicine, the leading edge of medical progress in autism treatment remains quite improvisational, making it harder to distinguish from CAM treatments. Clinicians need to be clear about what scientific studies show about the efficacy of available treatments both behavioral and biomedical, and address patient and hopes sensitively, but should not rush to judgment with regard to CAM treatments. Some, 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.

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

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.

Care 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 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).

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

Some typically-developing brothers and sisters develop close connections with their siblings with autism; some withdraw as adults and have little contact; most face a range of emotions from protective and caring to frustrated, angry, sad, or bitter. 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.

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. 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. 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.

These steps can help prevent the all-too-common circumstance where, later in life, parents die and siblings are suddenly faced with guardianship of a sibling whom they may barely know, particularly if they never developed a close relationship.

Discussion

As the numbers of individuals with autism increases, 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, and good clinical ethics and education are imperative. The 33-page guidelines document, available for free download (<http://stonybrook.edu/bioethics/stonybrookautismguidelines.pdf>), is not intended to be the final word, but to suggest areas worth more systematic social scientific investigation.

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