



Markkula Center
for Applied Ethics
at Santa Clara University

**Assessing Decision-Making
Capacity for Female Patients
with Autism**

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INTRODUCTION

Assessing patients' capacity to make medical decisions for themselves is fundamental to informed consent and expresses respect for autonomy. While competence is determined by the courts, capacity assessments fall on the shoulders of healthcare providers. Capacity assessments boil down to four key elements: understanding, appreciation, reasoning, and communication. In many cases, capacity is easily assessed. However, the assessment of whether a patient has the intellectual capacity to make their own medical decisions is not always performed consistently, and the conclusion of such assessments is not always obvious. Some patients and circumstances present an unclear picture of capacity. The presence of neurodivergence in patients can complicate capacity assessments, whether the cause be true capacity impairments, social stigma, or lack of established criteria. While there are many patients with impaired capacity that go undetected, on the opposite end, there are also many patients who are inappropriately and unfairly assumed to lack capacity due to diagnosed neurodivergence. Capacity is uniquely difficult to measure, as it is largely dependent on factors relative to each individual and situation. The subjective nature of capacity assessments and lack of consistent criteria make space for misjudgements and discrimination.

Healthcare disparities commonly place serious burdens on members of the disability community in the United States. Adults with developmental and intellectual disabilities, particularly women, are commonly assumed to lack capacity to make medical decisions which greatly affects the clinical care they receive. In the context of sexual and reproductive healthcare, many women with disabilities lack access to adequate and equitable care. The historic sterilization of women with intellectual disabilities and oppression of the disability community has undermined the U.S healthcare system's current ability to effectively care for women with neurodivergence. Women with intellectual disabilities regularly face assumptions of asexuality, dependence, and childishness. The objective of this research paper is to evaluate how adult, female patients with autism are assessed by physicians for capacity in sexual and reproductive medical decisions.

METHODS

Participants and Recruitment

Participants had to be either current or retired medical clinicians in the United States (n=13), family medicine (n=6), pediatrics (n=2), internal medicine (n=3), cardiology (n=1), and psychiatry (n=1). Physicians were recruited via convenience sampling. Physicians who were personally known by researchers or recommended by previous interviewees were contacted by email with requests to participate. Providers worked across the United States in different hospital systems, primarily in the states of New York, Washington and California. 15 physicians were contacted and 14 of them participated.

Study Design

Semi-structured qualitative interviews were conducted over three months (Jan-Mar 2022) either over zoom (n=12) or by phone (n=2). Physicians were allowed to choose their mode of participation for accommodation purposes. Interviews were brief, lasting 15-25 minutes each. Interviews were not recorded. Physicians were introduced to the study as an exploration of how physicians communicate with patients on the Autism Spectrum. Professional experience with patients with Autism Spectrum Disorder was not required. Physicians were presented with a personalized case study, created for the study's specific goals, and asked to respond as though they were faced with the situation in their line of work.

“Sarah” is a 29 year-old woman living in the Bay Area with moderate autism spectrum disorder, diagnosed as a toddler. Sarah works part-time at a local grocery store and has been living alone with financial assistance from her parents. Although she enjoys keeping busy with her job, she also paints, watches television, and takes walks in the neighborhood during the week. She has regular support from her family and older brother for regular transportation (she does not drive), financial stability and social interaction. Sarah does not talk very much, using fewer words than most and displaying difficulty communicating with people outside her family. Accompanied by her mother today who scheduled the regular check-up appointment, Sarah is in generally good health. To her mother's surprise, Sarah mentions pregnancy and wanting a baby. Sarah's mother immediately starts to shrug off this desire, but Sarah is adamant about her wishes to have a baby. Mother feels strongly that she is not capable or fit to take care of a child, and recommends birth control instead.

Physicians were then asked these questions over the course of the interview:

- 1) What types of questions would you ask Sarah and her mom?
- 2) How would you approach this situation?
- 3) How would you overcome communication related barriers?

Data Collection and Analysis

Notes were diligently taken throughout each interview, identifying major trends and noteworthy perspectives. After completion of the interview, physicians were then assessed and scored in accordance with eight categories associated with the ethics of capacity assessments, communicating with patients on the spectrum, and other considerations:

- 1) Understanding
- 2) Appreciation
- 3) Reasoning
- 4) Communication
- 5) Addressing Sarah directly & participatory decision-making
- 6) Preservation of autonomy
- 7) Beneficence

8) Consideration of the future child & mother

Physicians were given a score between zero and five for all 8 categories directly following the interview's completion. Scoring data was then used to identify trends and themes in the interviews.

	5	4	3	2	1
Understanding	Strong grasp of Sarah's level of understanding of the relevant information, her options, risks & benefits of pregnancy	Solid grasp of Sarah's understanding of the relevant information	Decent grasp of Sarah's understanding of the relevant information	Minimal attempt/bare minimum to gauge Sarah's understanding	No attempt to gauge Sarah's understanding
Appreciation	Strong attempt to gauge whether Sarah understands the gravity of her request; questions of the future and what it means to have a child?	Solid attempt to gauge whether Sarah understands the gravity of her request	Decent attempt to gauge whether Sarah understands the gravity of her request	Minimal attempt/bare minimum to gauge Sarah's appreciation of the situation and medical consequences	No attempt to gauge Sarah's appreciation of the situation and medical consequences
Reasoning	Strong attempt to gauge key factors/issues that contribute to Sarah's decision-making	Solid attempt to gauge key factors/issues that contribute to Sarah's decision-making	Decent attempt to gauge key factors/issues that contribute to Sarah's decision-making	Minimal attempt/bare minimum to gauge Sarah's reasoning regarding treatment options	No attempt to gauge Sarah's reasoning regarding treatment options
Communication	Strong effort to communicate with Sarah and assist her in communicating the provided info back to the physician; creative and thoughtful problem-solving to maximize communication potential with Sarah	Solid effort to communicate with Sarah and assist her in communicating the provided info back to the physician	Decent effort to communicate with Sarah and assist her in communicating the provided info back to the physician	Minimal attempt/bare minimum to decipher Sarah's ability to communicate her; mostly talks to mother	No attempt to decipher Sarah's ability to communicate her choice; only talks to mother
Addressing Sarah directly & Participatory Decision-making	Speaks to Sarah directly making eye contact; asks to speak to Sarah alone or insists on creating a safe space and opportunity for her to speak	Mostly speaks to Sarah directly and shows solid effort to engage her in the conversation	Partly speaks to Sarah directly for maybe half the time; decent effort to engage her	Slight attempt to speak to Sarah, but mostly reliant on mother for information and decision-making	No attempt to speak to or acknowledge Sarah's presence
Preservation of autonomy	Authentic support of Sarah and her role in determining her medical care regardless of ultimate outcome; informed consent is achieved	Solid support of Sarah and her role in determining her medical care regardless of ultimate outcome; informed consent is achieved	Partial support of Sarah and her role in determining her medical care regardless of ultimate outcome; informed consent is achieved	Minimal inclusion of Sarah and her desires in the decision-making process; unclear if informed consent is achieved	Completely excludes Sarah from the decision-making process; full reliance on mother to determine Sarah's medical care; no informed consent

Beneficence	Strongly behaves in the best interest of the patient first and foremost; in defense and support of Sarah's human rights; an advocate for Sarah	Mostly behaves in the best interest of the patient first and foremost; in defense and support of Sarah's human rights	Partly behaves in the best interest of the patient first and foremost; in defense and support of Sarah's human rights	Minimal consideration of Sarah's best interest and well-being in general; potential for harm	Very little consideration of Sarah's best interest and well-being in general; harmful approach to her care
Consideration of the future child & mother	Strong consideration of the impact of future medical treatment/ pregnancy on mother; strong consideration of the well-being of potential child	Solid consideration of the impact of future medical treatment/ pregnancy on mother; solid consideration of the well-being of potential child	Partial consideration of the impact of treatment on both mother and child	Minimal regard or consideration of the impact of treatment on both mother and child	No regard or mentioning of the mother or future child

RESULTS

Rubric Results

	5	4	3	2	1
Understanding	53.85%	38.46%	7.69%	0%	0%
Appreciation	53.85%	30.77%	15.38%	0%	0%
Reasoning	30.77%	38.46%	30.77%	0%	0%
Communication	30.77%	23.08%	46.15%	0%	0%
Addressing Sarah directly & Participatory Decision-making	61.54%	38.46%	0%	0%	0%
Preservation of autonomy	46.15%	38.46%	15.38%	0%	0%
Beneficence	61.54%	38.46%	0%	0%	0%
Consideration of the future child & mother	38.46%	53.85%	7.69%	0%	0%

Key Trends

	All participants (n=13) n(%)	Family medicine (n=6) n(%)	Pediatrics (n=2) n(%)	Internal Medicine (n=3) n(%)	Cardiology (n=1) n(%)	Psychiatry (n=1) n(%)
Desire to speak to Sarah alone	n=8, 61.54%	n=4, 66.67%	n=2, 100%	n=1, 33.33%	n=0, 0%	n=1, 100%
Desire to speak to Mom alone	n=3, 23.08%	n=2, 33.33%	n=1, 50%	n=0, 0%	n=0, 0%	n=0, 0%
Significance of continuity and established rapport/trust	n=13, 100%	n=6, 100%	n=2, 100%	n=3, 100%	n=1, 100%	n=1, 100%
Provided detailed guidelines for ideal communication beyond requiring time	n=4, 30.77%	n=2, 33.33%	n=2, 100%	n=0, 0%	n=0, 0%	n=0, 0%
Plan to make extra time to meet with Sarah during visits	n=2, 15.38%	n=1, 16.67%	n=0, 0%	n=1, 33.33%	n=0, 0%	n=0, 0%
Desire to meet with Sarah again to discuss pregnancy	n=13, 100%	n=6, 100%	n=2, 100%	n=3, 100%	n=1, 100%	n=1, 100%
Mention of child & its potential well-being/future	n=6, 46.15%	n=2, 33.33%	n=0, 0%	n=2, 66.67%	n=1, 100%	n=1, 100%
Concern for Sarah's safety (abuse, coercion, etc)	n=4, 30.77%	n=1, 16.67%	n=1, 50%	n=1, 33.33%	n=1, 100%	n=0, 0%

DISCUSSION

Understanding

Patients must understand the basic and relevant information such as the risks, benefits and treatment options. The majority of interviewed physicians prioritized assessing Sarah's understanding at the start of the hypothetical meeting. It's essential that providers explore Sarah's understanding of pregnancy and childbirth. *Does Sarah know how to get pregnant and what pregnancy entails? What does sexual activity mean to her? Does Sarah understand what it entails to give birth? What does it mean to Sarah to be a mother?* These are all key questions that could gauge Sarah's understanding of her desire to have a baby and the multifaceted demands of pregnancy. It's crucial to ensure Sarah has an understanding of the risks of sex as well. Safety is of the utmost priority. One can assume that Sarah has the capacity to give valid consent to sexual intercourse. The medical standard of capacity does not extend to Sarah's capacity to assent to sexual intercourse; however, it does encompass artificial insemination decisions. As a physician, it's critical to ensure sure that patients, particularly those with intellectual disabilities, are aware of sexually transmitted infections and how to participate in safe sex. All 13 physicians asked at least one question to assess Sarah's understanding. It's essential that providers comprehensively investigate Sarah's understanding of pregnancy and childbirth.

Appreciation

Patients must appreciate the situation and the medical consequences. In Sarah's case, it's valuable to gauge whether she understands the responsibilities of pregnancy and motherhood. A couple of the physicians who were interviewed who were also mothers expressed sympathy with Sarah's situation. Taking care of a child, especially a baby, is an enormous amount of work. Motherhood, especially if one parents alone, requires lots of multi-tasking, time management, financial security, and emotional support. As one physician said, "It takes a village." It's important that Sarah appreciates the concerns of her mother and family. Sarah relies on her family for financial support, transportation, friendship and support. Given that she is not fully independent, some of the physicians who were interviewed tried to explore Sarah's grasp on the extent of her independence and how that would impact parenthood. *Is Sarah willing and able to take care of a child if her family withdraws that support? If Sarah's partners offer to help, does she understand the impact her decision will have on her family?*

As a physician, it's essential to explain the risks and dangers of pregnancy itself. Some physicians expressed concerns about how pregnancy would disrupt her routine and bodily autonomy. *Routine and consistency are particularly valuable to people on the autism spectrum. What happens if the pregnancy leads to medical issues for herself, the fetus, or future child? How will Sarah respond to sleepless nights and a disruption of her weekly routine?* Most physicians dedicated time to gauging her appreciation of the seriousness of having a child as they explored

what having a baby would mean to Sarah. Having a child is an immense, life-long responsibility that many physicians were concerned Sarah did not fully comprehend.

Reasoning

Patients must reason about treatment options. This element of capacity fundamentally involves getting to the bottom of why Sarah wants to have a baby. Where is this desire to have a baby coming from? Why do you want to be a mother? These questions allow physicians to get to the core reasoning behind Sarah's request. Concern about Sarah's safety and potential abuse was a noteworthy trend. Four of the thirteen physicians expressed worries about abuse and coercion underlying Sarah's reasoning. This trend produces a double-edged sword. On one end, questions of Sarah's safety could be problematic if grounded in the perception of women with intellectual disabilities automatically being viewed as potential victims of sexual predation or exploitation rather than sexual beings with sexual interests. Assumptions of vulnerability and weakness feed into the present lack of adequate care, contributing to less access to preventative care or sexual education. On the other hand, limited research does indicate that women with intellectual disabilities experience higher rates of sexual abuse and abusive relationships than neurotypical women. It is vital that the concern for Sarah's safety be rooted in the demonstrated research and genuine concern rather than internalized stereotypes. Patient safety is paramount.

Many physicians began by asking about Sarah's relationship status and sexual activity at the beginning of the hypothetical encounter. *Do you have a special someone? Do you have a boyfriend? What does sexual activity mean to you?* Depending on Sarah's response, the conversation could evolve in several potential directions. Sarah's case raises questions of the power of implicit bias and physician's perception of autistic adults' parenting ability. Mistaken assumptions about adults with intellectual disabilities being poor or unfit parents are unfortunately common and often unfounded. However, it is appropriate for physicians to try to get a picture of Sarah's situation and if she'd have help from a partner in raising a child. Parenting is one of the most challenging roles a person can take on, especially alone. The interesting question is whether it is the physician's role to assess Sarah's parental fitness along with her capacity. Outside the realm of procedural decisions, such as medical questions regarding IVF or fertility treatments, it may be appropriate for a physician to help a patient make a complicated decision using a shared decision-making model. However, it may be outside the realm of the physician's duties to dictate whether a person should have children or not on the basis of neurodivergence, assuming there is no medical need to abstain and no invitation to assist in the decision-making process.

The most asked question explores *why* Sarah wants to have a baby. *Are her desires more superficial and recent, or are they deeper and of longer duration?* Some physicians questioned the legitimacy of her desire to be a mother, wondering if she was simply inspired by seeing some child on a playground or even a movie. One physician questioned whether she actually wanted a

child, or a teddy bear. To satisfy this wonder, one physician suggested that Sarah start working at a daycare first to test out the seriousness of her desire. Another proposed she start with a pet before jumping to have a baby. In contrast, it is possible that Sarah has roughly the same reasoning as any other parent. She may desire to start a family and enjoy the joys of guiding a new person through life. She may want to love a child of her own just like her parents love her. It is human to desire intimate relationships and reproduce. Disability stereotypes can unethically trigger the withholding of reproductive services and prenatal care, regardless of the patient's illustrated ability to provide safe and adequate care to a future child.

Communication

Patients must communicate a choice. Every interviewed physician expressed the significance of an established relationship and rapport, assuming they had already known Sarah. It can take time to learn how patients on the spectrum communicate with others and their preferred communication styles in medical settings. Autism spectrum disorder is an incredibly broad diagnosis, encompassing myriad styles of communication. As a provider, it can be a challenging and slow process to learn how to best communicate with their autistic patients. Hospital and office visits can be particularly stressful and anxiety-inducing for patients on the spectrum. In many instances, office visits do not allow a sufficient amount of time to have thoughtful communication with patients on the spectrum. Two interviewed physicians planned on making extra time to meet with Sarah during visits. One physician suggested scheduling Sarah at the end of the day, allowing for her visit to go beyond the regular time constraints. Patients like Sarah who are verbal but have more trouble communicating would greatly benefit from at least ten or fifteen extra minutes, especially for discussions about pregnancy and motherhood. Giving patients extra time to think through and process what they are being told and how it makes them feel can make a huge difference. All the physicians stated that it would be beneficial and even necessary to meet with Sarah again to discuss pregnancy.

Given that Sarah was accompanied by her mother to the appointment, and that the mother opposes the idea of Sarah having a baby, it's crucial for providers to speak with Sarah alone. The majority of physicians, about 60%, said that they would ask Sarah if she wanted to speak one on one without mom in the room. Giving patients the option of speaking privately when accompanied by a family member or friend makes space for more honest and forthright communication. Given that Sarah's mother disapproves of her desire, it's possible that Sarah would not be comfortable speaking about her sexual activity nor desires with the mother present. If Sarah prefers to have mom in the room, her wishes must be respected. However, it's important to give patients the option to speak privately, even if parents or guardians would prefer to be present. One physician eloquently emphasized that Sarah is her patient, *not* mom. Providers have a duty to serve Sarah and honor her wishes, even if it differs from the desires of guardians. Although, it's crucial to note that Sarah's mother and the rest of her family are important players in her life that would be heavily impacted by Sarah having a child.

While all thirteen physicians said it was a priority to get to know Sarah for communication purposes to better understand her particular mode or modes of communication, only four physicians described detailed guidelines to ensure ideal communication with Sarah. When asked to expand on how they would overcome communication related barriers, many physicians struggled to answer beyond being patient and giving time. Although time is a key factor, there are many other components that contribute to enhancing communication between patients with autism and their providers. First, it's helpful to gauge Sarah's language and match it, using language appropriate to her. Providers should avoid medical jargon and instead use Sarah's words, as in words that are familiar to Sarah. One physician creatively mentioned learning the *patient's* definitions and meanings of words, rather than assuming their two definitions align. Similarly, it's important to respect and match the patient's pace. This may require speaking more slowly, taking longer pauses, or asking more questions to make sure the patient is on the same page. In the case of adult patients with neurodivergence like Sarah, these suggestions in no way suggest that providers should talk down to their patients or treat them as children. Patients should be spoken to as equals, like any other adult patient. Prioritizing patience, listening, and clarity in regard to communication are extremely valuable to maximizing honesty, trust, comprehension, and patient comfort.

Concern for Mother & Future Child

The mother and future child are key stakeholders in this ethical situation. Whereas the majority of physicians asked if Sarah wanted to speak privately, only three asked to speak with the mother alone. Of the three physicians, only one asked to speak to mom alone while the remaining two asked both parties to speak one-on-one. Those who asked to speak alone with Sarah expressed the importance of validating mom's concerns and fears for Sarah. *Why does mom feel that Sarah is not fit nor in the position to be a mother? Does mom and family worry that they would end up becoming the child's primary caretaker?* Sarah is not financially independent and is presently supported by her parents, so it's likely that the parents would end up financially supporting Sarah's child. It's also possible that Sarah is not being fully forthright with her physician. Despite being *Sarah's* doctor, it's important to hear what mom has to say without allowing her to dominate the conversation. Both Sarah and her mother should feel heard and supported. It is understandable why physicians would want to speak with mom alone; however, this may jeopardize the established trust and honesty between Sarah and her provider. While the mother has a morally legitimate interest, the primary relationship to be fostered is between Sarah and her physician. Maintaining patient trust remains of vital importance. Sarah's situation suggests that asking to speak with a parent or guardian alone, without the patient present, may produce more risk than reward.

Less than half of the physicians considered the future child and its potential well-being during interviews. Sarah is the sole patient and she must be the priority. However, it is appropriate for a

provider to protect potential children's safety and interests. Connected with gauging Sarah's development, and concerns that her desire for a child isn't an enduring one, one physician worried that the child wouldn't be adequately cared for and loved. This physician worried that Sarah's potential child could be exposed to potential trauma. I'm sure physicians would have similar concerns if they came across an incredibly rude, selfish, unempathetic patient, or a patient who had trouble taking care of themselves, or a patient facing addiction. A physician should never tell a patient that they should not have a child simply on the basis of a developmental or intellectual disability. One physician stated that it is not her place to decide whether a patient can be a parent or not. Another physician said that she would never tell Sarah she cannot have a baby. Unless having a child would be medically dangerous for the patient or the child would be entering an unsafe situation, it is not the provider's job to determine parental fitness.

Comfort & Experience

It's essential that people with disabilities are treated, simply, as people...not as oddities, abnormalities, nor burdens to the healthcare system. Similarly, adults should be treated as such. People must not be identified solely by their disability, just as someone should not be solely defined by any other medical diagnosis. Patients should be included in the decision-making process as active participants. Even if accompanied by a parent or guardian, the patient should be the primary focus of the meeting. The majority of interviewed physicians strongly emphasized speaking to Sarah directly and actively involving her in the decision-making process. Some physicians stressed the importance of limiting the mother's role in the conversation, ensuring that she does not dominate the limited time one has to speak with Sarah. It's fundamental that patients feel heard, valued, and respected during important healthcare conversations. All of these components can improve patient experience and patient outcomes.

Study Limitations & Future Implications

There are limitations to the study that should be acknowledged. First, the study only used one case study with a decently specific circumstance that cannot be representative of all people with developmental disabilities nor sector of care. In addition, nearly half of the interviewed physicians specialize in family medicine. The spread of specialties was not even, heavily emphasizing family medicine with little representation from other specialties. In regards to methodology, the interviews were more loosely structured in terms of guiding the responses. The few questions asked were open ended, allowing physicians to respond without limiting structure or direction. As a result, the rubric's nature was also fairly subjective, judged by a single interviewer's perception of the ideal approach to Sarah's situation.

Patients with developmental disabilities face numerous barriers to accessing adequate and equitable healthcare. We live in a society that is built for able-bodied, neurotypical people. People with disabilities experience significant disparities in healthcare while disproportionately

seeking medical care. Addressing present communication issues, particularly in the context of verbal limitations, is a crucial step towards improving the effectiveness of healthcare delivery and quality to patients like Sarah on the autism spectrum. Although this study does not touch on it, healthcare providers also must acknowledge implicit bias and internalized stereotypes against people with developmental disabilities. Finally, providing clearer education and consistent criteria for conducting capacity assessments will help prevent cases where patients are unfairly judged as incapable or inappropriately found to have capacity.