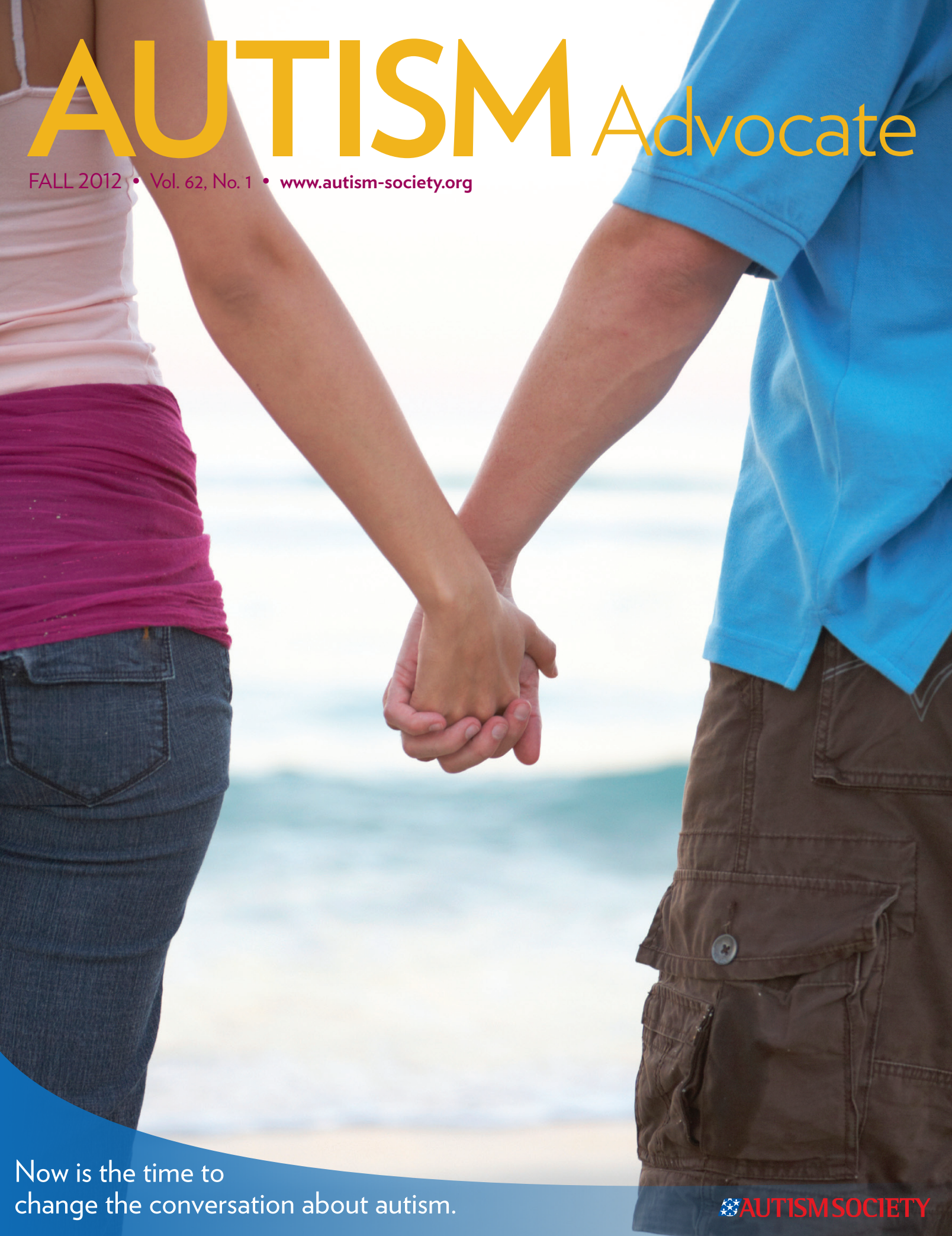


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9 Essential Ingredients to Maintaining a Successful Relationship: *The ASD Edition*

Being involved with a romantic partner for six and a half years can teach you a lot about a relationship. But a coincidental opportunity to share our story with the national media has helped me to understand a lot more about how we make our relationship work.

It all began when we were approached by Glamour magazine. They were seeking to profile a couple living with autism (ASD) for their March 2009 issue. Dave and I had already been dating for 3 years and were sharing an apartment. We already had figured out our strategies for relationship maintenance, and we had been presenting at autism conferences and workshops on the topic. However, we never thought through exactly how we made our relationship work, and we never thought through the specific challenges and strengths.

Since the publication of that article, we have participated in additional in-depth interviews (Good Morning America, NPR, and the like). We have also remained active within the autism community and regularly present at conferences and workshops across North America.

Being under the public eye has been an educational and surreal experience. Our interviews with journalists and reporters have served as a near-equivalent to complimentary couples counseling. These journalists and reporters have never been invasive, but they have asked us to elaborate and respond to some excellent questions that every couple would benefit from looking into.

When it comes to autism and romance, generic relationship advice is overrated. What I have discovered to be far more effective is being authentic. Authenticity often shines best when you simply share what 'ingredients' have worked for you, and allow your audience to make up their mind on how to take what you've shared.

Here are 9 essential 'ingredients' to how Dave and I make our relationship work:

1. **We learn the rules. Then we break them.**

As a pianist and composer, I can relate to this principle. My performing and writing style is highly abstract and I don't follow the protocol of a conservative piano recital. However, it took 13 years of classical training

••• ► By Lindsey A. Nebeker

to know how to break those rules.

Securing a lasting relationship usually requires securing interpersonal skills, which means doing a little homework on our part.

People on the autism spectrum have trouble understanding the interaction of the peers that surround them. We wonder how our surrounding peers are able to communicate to each other while we are not able to communicate with them. This is what I like to refer to as the Social Antenna Theory. Those of us with autism do not arrive in this world equipped with the social ‘antenna’ that other people seem to have naturally acquired. They use their “antennas” to pick up signals on things like social nuances and nonverbal queues, and other indirect forms of communication we don’t pick up on. We have to build our own “antennas” and learn how to conduct our signals where we can connect to the signals surrounding us.

The tools and materials that we have to collect to build our “antennas” consist of an endless supply of scripts. Examples of scripts include reading material, media, and careful observation. Scripts can provide insight into a variety of skills -- especially skills which involve interaction with other people. Dating and relationship skills require learning effective people skills. In other words, you have to secure a trusting friendship with your partner to successfully maintain a romantic relationship. When Dave and I were growing up, we both struggled with making and keeping friends. We invested years of hard work towards reaching that goal, and we feel that effort has served as an advantage to our current love life.

It’s important to note that love between two people on the autism

spectrum carries its own unique characteristics. This is why it is encouraged to deviate from those rules. However, to break the rules, you need to study the rules first.

2. We accommodate our sensory issues and needs.

We have open conversations about our individual needs, and figure out how to accommodate each other’s needs. Nearly every one of us on the spectrum has our own ‘wiring’ in our nervous system that result in particular sensory sensitivities and sensory violations.

Couples who live together may want to discuss things like...

- ♥ Thermostat settings
- ♥ Lights
- ♥ Wall color(s)
- ♥ How loud you like your TV or music player
- ♥ Sensitivities to certain aromas (food, room spray, perfume, etc.)
- ♥ Pet allergies

Take lighting, for example. Dave prefers to use energy-saving bulbs for conservation purposes. I have always used incandescent lighting, since energy-saving bulbs don’t look as natural. White fluorescent tube lighting is also painful to my eyes, and leaves me nauseated, irritable, and feeling like I’m visiting an interrogation room. When we moved in together, we combined our lighting so that each common area (living room, office, dining room, kitchen, etc.) had at least one lamp with an energy-saving bulb and one lamp with an incandescent bulb.

Taking an inventory of each other’s sensory profile (hypersensitivities and under-sensitivities) will help determine approaches in conversational, social, and intimate relations. Knowing each other’s

sensory profile not only prevents sensory violations, but can also serve as an advantage. We both happen to find exploring scents as therapeutic (Dave is especially drawn to lavender). He and I will occasionally pay a visit to a Yankee candle store and wander off to a ‘smelling spree’.

Strategizing ways to accommodate each other is a good lesson in compromise. Compromise is one of the most difficult concepts for individuals with autism to break into, but if we make an effort to meet half-way, it becomes evidence of unconditional love.

3. We establish effective communication.

For any relationship to succeed, effective communication is crucial — whether it be written, oral, or alternative format. When a topic involves a simple “yes” or “no” response or can be answered in a few sentences, then we address it right then and there. When a complex topic needs to be untangled, we schedule a time to discuss it. Focusing on one topic at a time is ideal.

Here are other ways Dave and I make an effort to effectively communicate:

- ♥ Being honest and open about our feelings.
- ♥ Asking how much advanced warning is needed to prepare for developing changes, and provide that warning accordingly.
- ♥ Laying out complex and detailed tasks and discussions in written communication, in place of oral communication (email, handwritten notes, messaging, texting).
- ♥ Listening and minimizing interruptions during a conversation.

♥ Playing fair and listening to both sides in the event an argument occurs.

4. We plan things out in advance.

Dave and I both had previous experience with roommates during the college era, but when a couple moves in together, it's a big statement. Several months were invested into the planning process. We discussed in detail the modifications and changes that would take place — from the decor to the bedrooms to the setting on the thermostat — even the placement of lamps with our particular light bulbs....

Prior to moving in together, we did a few “cohabitation experiments” — up to 2 weeks at a time. I drew out a floor plan to visualize where everything would be once our belongings merged.

As much as you can invest in preparing to accommodate each other's needs, there are some things you just won't know until after you start living together. We make an effort to keep the communication open in the event we do run into a sensory or related needs issue.

For some couples, intimacy has to be scheduled in advance. This may sound unromantic, but especially in the beginning stages, spontaneity can

be tricky to navigate.

5. We cultivate companionship and practice compromise.

Falling in love may come naturally, but companionship is an art that has to be cultivated and nourished. Dave and I were coming from two fairly rigid lifestyles, and we both had our particular daily routines. Our obsessions, rituals, and preferences tend to clash like as if one was to try and combine elevator music and gangsta rap.

Compromise will always be a ‘work in progress’, but it is an incredible teaching tool in strengthening a

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relationship and strengthening companionship. As time progresses, it gets a little easier.

6. We recognize independence and individuality.

For the past 4 and a half years, Dave and I have been living under the same roof, sharing a life together -- as two individuals, with separate preferences, separate routines, separate interests, separate decorating styles, separate sensory sensitivities ... the list goes on.

We make an effort to accommodate our established rituals and routines.

For individuals with autism, routines and rituals provide a sense of calm, consistency, and self-control in a world where we don't have much outside control.

Although I do wish that Dave had as much appreciation for my interests as my other friends have, I accept that he's entitled to be fixated to his own interests.

Having said this, it is important to have a balance of companionship and independence.

We have a joint account, but we also have our own checking and savings accounts. We split expenses on household utilities (based on income percentage), yet we buy our own groceries. We collaborate on house cleaning duties, but we do our own laundry.

It's true that relationships involve teamwork. However, a couple still consists of two separate identities, and that needs to be respected.

7. We respect each other's personal space.

For a couple with autism, space is not overrated. Inside the living space, it is essential to dedicate at least one

area per person inside the living space to retreat to when he/she wants to be alone. Having our own dedicated personal space allows us to maintain the lifestyles we were previously used to.

Dave and I have gone so far as to establish our own bedrooms. Dave's furnishings are retro-oriented, while mine are Asian contemporary. We have slightly different mattress preferences. Our sleep cycles are more easily managed, since our work shifts are not consistent. We can keep our spaces at our preferable temperature ranges (he likes his room around 65

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degrees, I like my room between 70-73 degrees). Most importantly, having our own dedicated space serves as a retreat to fulfill our occasional need of solitude. We respect and recognize that solitude is essential to our physical and emotional health.

8. We take our time with transitions.

Conversations on the 'm-word' (a.k.a. marriage) is awkward for both of us. Sure, we can discuss future planning ... on things like what we plan for house renovations and trips we'd like to take someday. Marriage, to us, is a life-changing transition.

Transitions are not easy, no matter how great or small. Life transitions take even more time to adjust to. It involves making complex decisions, which can be overwhelming for individuals with autism to take in and process. Life transitions include

the steps taken towards committing to a lifelong partner. This can include cohabitation, intimacy, sex, engagement, marriage, and raising children. Every transition involves making decisions.

However, it's nearly impossible at this point for Dave and I to avoid the topic. When a couple has been together for six and a half years and speak with allies, family members, and fellow individuals on love and dating within the spectrum, questions on engagement, marriage, and family-planning are guaranteed.

What is essential is not so much when, how, or even if you take all those particular steps in your relationship. What's essential is that you need to have a solid reassurance of commitment. This reassurance can be expressed and in a number of ways — through verbal or nonverbal communication. Examples of reassurance include (but not limited to): having an uninterrupted conversation, writing a sincere letter, or displaying affection (if you and your partner like touch).

Life transitions are not to be taken lightly, but it is good to remind ourselves it is okay to take some risks. My father often reminds me: "If you don't go for it, you may never get another opportunity to have that experience. And you'll always question what would have happened had you gone for it."

Our most recent life transition took place this past year, when we became first-time home owners. So far we have adjusted well to that phase of our life together.

9. We embrace the unconventional.

There are certain guidelines that need to be followed in any relationship, regardless of disability.

However, in relationships between individuals on the spectrum, unconventional is cool. One example I have already mentioned is having our own bedrooms. Another example is how we express love for one another. Strong emotions that expose our vulnerability are often overwhelming and tough to express.

Looking at Dave in the eye can sometimes be painful for me.

Although Dave is more touchy-feely than I tend to be, exchanging affection has rarely been an issue. Nearly every night before we go to sleep, we remind each other how much we love each other. But he has pointed out to me (and rightfully so) that I will more likely close my eyes and slip the casual “Love ya” rather than look him in the eye and say, “I love you.” And when he points that out, I pause, fight the lump developing in my throat, and say softly, “Yes... it’s true. And I hope you can trust when there is a time I have trouble looking into your eyes, you will still know I love you.”

All that matters is that you recognize your love for each other, however it may be expressed.

In Closing...

We each have our unique characteristics, challenges and strengths that shape our identity. Each couple, whether one or both partners have ASD, will need to collect their own “ingredients” that make their relationship healthy and successful.

Why is it important to talk about love, relationships and sexuality when addressing the needs of individuals with autism? The reason is simple — human rights. Sexual rights are human rights. We need to recognize that individuals with disabilities have rights just like everyone else. This includes the right to establish a relationship, the right to marriage, and the right to raise a family (if one so chooses). The right to love and be loved is a basic human right. Human rights are the fundamental core of the conversation we need to have when it comes to addressing self-determination and full participation of individuals with autism throughout the lifespan.

When learning how to advocate for ourselves, it is important for us to know our rights. Not everyone has an interest in pursuing love, but it is important to know we at least have the right to pursue love.

The right to love and be loved is a basic human right. Human rights are the fundamental core of the conversation we need to have when it comes to addressing self-determination and full participation of individuals with autism throughout the lifespan.



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Lindsey Nebeker is a pianist/composer, disability rights advocate and speaker diagnosed with autism, currently working in the Washington D.C. area as a Development Specialist at the Autism Society. She was born in Tokyo, Japan, and moved to the United States at age 11. She also has a brother diagnosed with autism. Ms. Nebeker holds a B.A. Degree in Music Technology from the College of Santa Fe and is a Partners in Policymaking graduate. Since 2005, she has been active within the autism community by presenting at conferences and workshops in the United States and Canada. She has a specific interest in ASDs as it relates to relationship and sexuality issues, and often incorporates it into her presentations and writing contributions. Ms. Nebeker has been featured in Glamour, ABC’s Good Morning America, NPR, and appeared on the cover of Autism Spectrum Quarterly. In her spare time, Lindsey enjoys traveling, producing music recording projects, photo-shooting excursions, and spending time with her significant other, Dave.