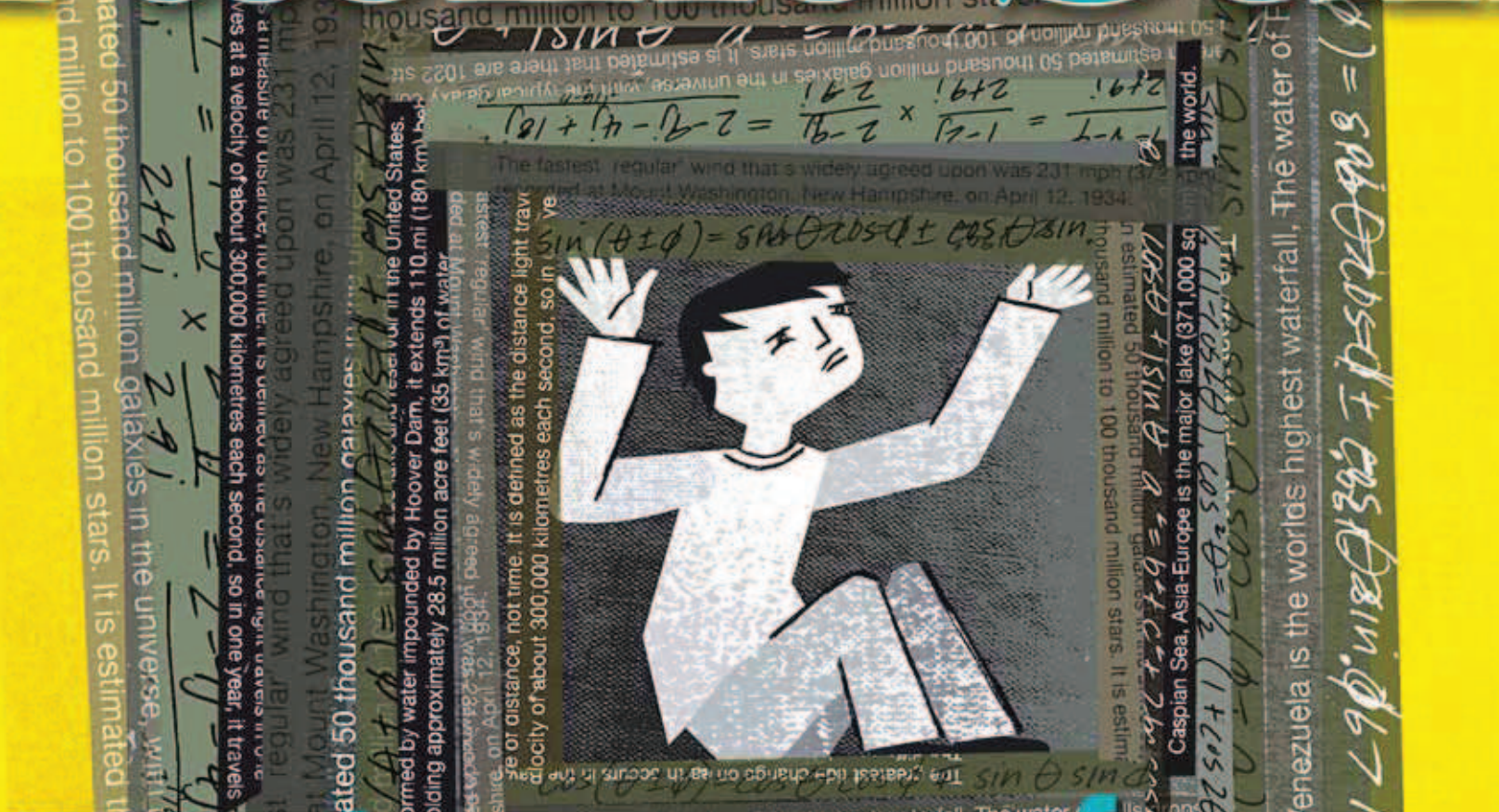


Pacific Sun



Autism comes of age [P.12]

The epidemic's 'first wave' braves the trappings of the adult world

QUOTE OF THE WEEK: **Americans know more about space than about the ground we live on...** [SEE PAGE 20]



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Autism enters adulthood

The number of autistic adults is on the rise—while help for them is falling short

by Linda Xiques

“Does this little girl live here?” A stranger stood on my doorstep holding the hand of my curly-haired 3-year old daughter, who was naked as a jaybird. “I saw her running down the street in front of my house.”

I scooped up my daughter, while thanking the neighbor profusely for bringing her home. As he turned to go, I noted a look of disapproval on his face that said, “bad mother.”

We’d just moved from a steep hillside house to a new home with a level play yard and a safe, high fence. Silly me, I thought that now I could take my eyes off my child for, oh, maybe five minutes at a time.

I knew little about autism at that point.

In 1971 when my daughter was born, the autism rate was one in every 10,000 births. Today, one out of every 110 babies is born with autism. In the last decade, the rate of autism has increased 20 fold and an estimated 1.5 million individuals in the U.S. are affected.

They are usually beautiful babies. Their oddities appear only later, when they may stop talking at 18 months, or resist being

touched or fail to make eye contact. They often develop peculiar behaviors, flap their hands in front of their faces, become fixated on a light switch or washing machine, or echo words said to them with no real comprehension.

Today, children with such obvious symptoms are recognized as autistic right away. There are assessment and early intervention programs to help parents understand and work with their child. These children are routed into special education programs and receive social services that follow them into adulthood.

But autism is a spectrum disorder, ranging from severe to mild. Some children and adolescents with autism spectrum disorders (ASD) are never thoroughly assessed and diagnosed. With deficits in social skills and an inability to plan and manage their lives, they are written off as failures or misfits when they become adults. They are prone to depression and at risk for suicide.

Each of these “beautiful babies” grows into an adult with the usual adult



In 1971, one in every 10,000 kids was diagnosed with autism; today it's one in 110.

needs—a job, a place to live, friends, an independent life. But is that a realistic hope for young adults with autism? Can they ever leave the family home? What happens when their parents die?

My 38-year-old daughter has a form of high-functioning autism known as Asperger's syndrome. Though her intelligence is in the normal range, she has both social and auditory processing deficits. She sometimes misunderstands what's said to her and gets angry as a result. Like many with Asperger's, her interests are very narrowly focused; she has good rote memory skills, but difficulty with abstract concepts.

Although capable in many ways, she is stressed by change or responsibility. We're told she's “not ready for a competitive work environment,” and deficient in “executive functioning.” The latter is the ability to see a problem, plan a solution and follow through. It's a skill that's very necessary for an independent life.

As the mother of a special needs “child,” I know a number of other parents who are responsible for their autistic adult children. Some of them qualify for services through the Golden Gate Regional Center, one of 22 regional centers serving individuals with developmental disabilities in California.



Autistry Studios offers four-hour workshops to help high-functioning autistic teens adjust to workplace environments.

About a boy

One family's autism diagnosis changed their lives in more ways than one...

Janet Lawson and Dan Swearington began conducting workshops through Autistry Studios in 2008. For Janet and Dan the last few years have been an incredible journey—from working with autistic students to parenting their own autistic child and then to Dan's late discovery that he too is on the autism spectrum. Lawson, a red-haired therapist with a warm and ready smile, and Swearington, a former astrophysicist of almost boyish charm, seem ideally suited to work with ASD kids. They never set out to do so, however. She studied filmmaking in college; his degrees are in physics and astronomy. Their goals changed when their son was diagnosed “autistic.”

When did you first learn Ian was autistic?

Janet: Ian was diagnosed when he was 3 years old. Before that, I didn't know *what* was going on with my son, but he was different.... He had a total fascination with hinges, would stare for hours looking at a hinge, or taking a piece of paper and rolling it over the edge of a table.

So when the doctor said he was autistic, it made sense to me. Not that it was a happy thing to hear. It was a Friday, and we took the phone off the hook for the weekend, and we cried for two days. We *wailed*, it was a keening pain. And on Monday morning, Dan went back to work and I

At 35, “Josh” is a big, strapping guy who is severely autistic and nonverbal. He lives at home with his parents, both highly skilled professionals, who are now retired. Josh has always been in special day programs, often with a one-to-one aide, but for the last eight months, his parents have cared for him 24 /7. Since he sleeps only five hours a night, that means nearly constant attention. They’ve been told there currently is no appropriate day program for Josh. Reluctant to place him in full-time residential care, his parents aren’t getting the support they need to keep him in their home. Both are exhausted and worried about his future.

Michael is an autistic man of 37 with “delayed language processing,” which means the quick pace of conversation is difficult for him. But when he opens his mouth to sing, it’s a different story. His rich baritone soars through complex classical works by Handel or Mozart; or he can strum his guitar and sing an early Bill Withers tune. He has performed at all sorts of fundraising events, and

recently participated in a special production of *The Wizard of Oz*. Once he steps off the stage, however, he’s back to being reticent Michael Valcour, locked in by autism. His parents are immensely proud of his accomplishments, but they worry about his life in years to come. Who will provide him companionship, supervision and guidance when they are gone? Where will he find the sheltered privacy he needs? Meanwhile, they devote much of their life to seeking opportunities for him to express himself through music. (The Valcour family email address is mikeval7@peoplepc.com).

“Katie,” at 22, is a slim, rather solemn girl, with a talent for drawing. She has been diagnosed with Asperger’s syndrome. Since being fired from her first entry-level job, she has sporadically taken classes at College of Marin. She does OK with one or two classes, but can’t handle a full schedule. Easily stressed or angered, she’s intelligent, but “has no common sense whatsoever,” according to her mother. She can’t keep track of money, makes irrational purchases and is

easily taken advantage of. Her parents hope eventually Katie can find a job that uses her artistic skill, perhaps within a structured, sheltered environment.

THE GOLDEN GATE REGIONAL

Center (GGRC) serves people with developmental disabilities in Marin by overseeing and funding local programs and service providers. Individuals with Down’s syndrome, cerebral palsy, autism or other serious developmental problems can get help with housing, skills training, social programs and case management. GGRC currently does not serve those with Asperger’s syndrome.

GGRC is under tremendous strain these days. The number of autistic clients is rising (statewide, the regional centers are adding thousands of new autism cases each year) at a time when state funding for the developmentally disabled is shrinking.

This year’s budget for the state’s regional centers was cut by \$334 million. All social programs for the disabled were canceled, and respite hours for parents also were reduced.

Speaking of the cuts, Tony Thurmond, who manages GGRC services in Marin, says, “Essentially the state wiped out funding for all social recreation: no camps, no bowling, no friends support groups, no dances, no funding for any program that will help young people explore relationships and friendships.... It’s difficult for families to hear us say we’d like to provide you more services, but due to the state crisis, these things have been cut.”

The state also imposed a flat 3 percent reduction in the revenue that programs and direct service providers receive. “That cut is huge for some programs,” says Thurmond. “At least one day program has already closed its doors in Marin County since these changes have been implemented.”

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IN A NATIONAL REPORT on the current state of services for adults with autism, the Organization for Autism Research notes “the first wave of what is typically referred to as the autism epidemic is rapidly approaching adulthood. This group represents only the proverbial tip of the iceberg... This is a looming crisis for families and the ill-prepared and underfunded adult service system charged with meeting their needs.”

Alarmed by such predictions, government entities, research centers and autism advocates are starting to plan for the future of this growing population. This year, the California Legislature set up regional taskforces throughout the state to survey the needs of those with ASD and to recommend legislation to help them. State Sen. Mark Leno, who heads the SF/Marin Autism Regional Taskforce, invited local autism activists to join taskforce committees on early assessment, training and employment, housing and insurance issues.

Nationally, a coalition of autism organizations just held its second National Town Hall meeting in November. The one-day, web-based conference on “Advancing Futures for Adults with Autism” drew hundreds of participants across the country, and was chaired by Mayor Richard Daley of Chicago. The goal was to elicit widespread input and winnow the results into “an actionable public policy agenda.”

Autism consultant Karen Kaplan serves on the housing committee of the Regional Taskforce and also participated in the National Town Hall conference. A petite woman of boundless energy, Kaplan has been working with autistic children for 30 years, first as a speech therapist and later as director of two private schools for those with ASD, in Sacramento and Marin. She’s encouraged by the national concern and cooperation 14 >



Karen Kaplan says autism support has come a long way since the 1970s when kids were still being institutionalized for the disorder.

got on the computer and starting researching autism.

Did your career path change at that point?

Janet: Absolutely. I was working in San Francisco designing information systems and when Ian was diagnosed, I cut back my hours to half-time, then to no time at all. I spent full-time just teaching him how to talk—and dealing with the schools. Which is a full-time job in itself. Advocating for your child, working with the schools on the best programs for him, it goes on full-time.

But that started our journey. From that time on, it changed our life.

Dan: Ian was originally diagnosed “low-functioning autistic,” which is the worst diagnosis they give. He had no speech at age 3.... He has outgrown that diagnosis, which in itself is extremely unusual. He’s still autistic, he’s still impaired, but he would no longer be considered “low function.” And he keeps learning and improving.... He’s always done better than we thought he was going to do, but we can’t tell how much better he will be, or how independent he can be.

You bring a wide array of talents to the workshops.

Janet: Well, my background is filmmaking. I went to the American Film Institute, worked at Paramount Pictures. But I’m also a programmer and designed information systems. Dan’s background is astrophysics, computer programming, and his major hobby is model building. I also sew and cook, and he builds cars, so between us we can pretty much meet the kids in whatever they want to do.

Dan: Again our motivation [for Autistry] has grown out of “oh, my God, what’s Ian going to do?” We could see there are programs for him through high school, but after that? We thought if he’s ever ready for college, it will be when he’s 30, not in his 20s.

And, frankly, that’s not terribly different from my profile. I wasn’t ready for college right after high school. I was one of those kids that got fired from all his early jobs and flunked out of college when I first tried to do it. And I didn’t understand why it wasn’t working.

My family just thought I was a loser. They wrote me off.

I finally worked my way into a job on the assembly line at Hewlett-Packard in Santa Rosa.

How did that lead back to college?

Dan: HP would pay for their employees to go to school if they wanted to. I found that if I only took one or two classes at a time, I could ace them. It was a question of how much class time and how many different threads I could maintain.

For me, it was two classes A’s, three classes F’s. College counselors did not get this. From their perspective, it should be two classes A’s, three classes B’s, 4 classes, C+, B-. But that’s not how it is for me.... So [later] at Cal State Northridge, I would take the fluffiest things I could find along with the upper research classes I was taking, to fill out my 12 hours, so I could still get financial aid. The 12-unit requirement to qualify for financial aid as a full-time student is a huge obstacle for most of our kids, because most of them cannot do a 12-unit load.

Janet: That’s one of the things we’re going to champion being changed for these kids—because that’s setting them up to fail. They can’t handle four classes at one time.

At what point, Dan, did you begin to wonder if you’re on the autism spectrum?

Dan: At that point [in college], I didn’t have any labels on me. Later on [after Ian’s diagnosis] I did some testing and my profile was what would now be called Asperger’s: extremely uneven capabilities on an intelligence test. Huge spikes of high capability, with other spikes of low, retarded capability in other areas.

that's developing around autism.

"I've been in this field since the '70s, and let me tell you, this wouldn't have happened then. In the '70s, parents were still being advised to put their autistic kids in a state hospital. So it's exciting that we're all now talking about autism."

Kaplan points to the Marin Autism Collaborative (MAC) as an example of local progress. In 2007, 150 service agency reps and autism advocates in Marin got together to form the collaborative. Facilitated by Lifehouse, an agency that serves the developmentally disabled, the group met to survey the available services in Marin and explore where the gaps exist for those with ASD. One obvious need was better access to information and resources for families dealing with autism. In 2008, MAC created a website, www.marinautism.org, that's chock-full of information. Parents can find a directory of autism support groups, specialists and care providers, as well as news and a calendar of upcoming autism events. The MAC committees continue to meet monthly to work on local ASD concerns.

• • • •

TWO NONPROFIT AGENCIES listed on MAC's resource directory are Lifehouse and Opportunity for Independence. The former primarily offers residential programs and the latter, skills training, but there is some overlap of their services.

Lifehouse, which used to be called MARC (Marin Aid for Retarded Citizens), was started in 1954 by a group of parents whose children had Down's syndrome. Executive Director Nancy Dow Moody says the agency still serves some of those original clients.

As a result of the rise in autism, Lifehouse has broadened the focus of its services. Moody explains, "We've hired a specialist in autism to work with our staff and train them, because people with



Lifehouse has two new programs in the works, says director Nancy Dow Moody—a recreation program for teens and a housing complex for adults.

autism learn a little differently than some of our other clients. We're trying to gain more expertise in serving that population and doing it well."

Lifehouse currently serves the entire autism spectrum. Some of the most severely disabled live in intermediate care facilities, which provide assistance with daily living, showering and eating. At the top of the spectrum, Lifehouse has some clients with Asperger's whose parents pay privately for case management services.

Moody points with pride to two new autism programs Lifehouse has in the works. One is a recreation program for teens with autism, made possible by a recent grant from Autism Speaks, a national advocacy organization. Another is a proposed housing complex for autistic adults in the town of Sonoma. An experienced developer, who has an autistic son, wants to build housing units that will eventually accommodate 16 individuals with ASD. Once the units are built, Lifehouse will supply support services

for the residents. Thus far, she says, Sonoma's planning commission has been very receptive to the plan.

• • • •

THE MAIN FOCUS of Opportunity for Independence is independent living and

vocational training for adults with disabilities. The agency provides adult day programs and a limited residential program. At some of the day programs, clients can earn money by doing piecemeal work for outside companies. A few OFI clients are autistic, but most are not.

Matt Tarver-Wahlquist is the director of OFI day programs. His chief involvement with autism is through MAC, where he is chairman of the subcommittee on transi-

tions. He also serves on Sen. Leno's SF/Marin taskforce.

"We've got this demographic time bomb ticking away," he says, "and the community, the regional centers and service providers are all trying to find creative ways to meet the coming needs."

Citing the difficulty of transitioning autistic adults into the workforce, Tarver-Wahlquist mentions an Asperger's individual who also is on the taskforce. "His story is a common one. He's very intelligent, very capable and skilled, but due to his disability he functions on a different set of social cues. He often alienates himself from others in the workplace, so he can't hold down a job.... When asked a question, he'll offer a very honest but tactless response, so he comes across as being blunt or rude. One thing that needs to happen is for employers to realize this is a disability and make accommodations for the social deficits that arise out of it."

One issue being discussed by the SF/Marin taskforce, says Tarver-Wahlquist, is "how can we get the regional centers to expand their umbrella across the whole autism spectrum, including Asperger's? That would be a logical and appropriate thing

to do.... Families can purchase services if they have the resources. But unless the individual has a wealthy family, there is nothing there for him."

Tarver-Wahlquist advises parents of autistic teens to

start early in planning their child's transition to independent life. When the school schedules an Individual Education Plan (IEP) meeting on transition, he says, "Be proactive. Talk to the social worker who knows what services are available and 18 >

... the first wave of what is typically referred to as the autism epidemic is rapidly approaching adulthood. This group represents only the proverbial tip of the iceberg... This is a looming crisis for families...

< 13 About a boy Uneven development is absolutely one of the characteristics of kids on the autism spectrum. They'll have capabilities where they are very good, often gifted, and other adjacent areas where they are abysmally poor. And if you force kids to spend too much time in the areas where they are poor, they just will not perform well.

Janet: And then their self esteem goes down and their peers see them as only failures—and they start getting into trouble, acting out. With our older kids, that can lead to drugs, to suicide. The risk of *not* helping these kids to develop their talents can be dire. All kinds of things happen to them.

So the Autistry workshops were shaped by your own knowledge of what it takes to adapt and grow.

Dan: What happens now in the workshops is what we consider *pre-vocational*. It's building skills and getting kids socialized to the workplace. So a lot of the rules that we impose are kind of standard workplace rules. If you're on the computer, you have to be doing *only appropriate things* on the computer. The meal break is really about getting used to eating with your co-workers and learning to have the kind of small talk you'd have at work. For instance, can they hold a knife and fork properly? I have to tell you, about half can and the other half *can't*. You put a piece of chicken on their plate and the most amazing things happen in terms of how they get that to their mouths.

How is your workshop different from other programs?



Dan's work with Asperger's teens helped him recognize his own symptoms of the disorder.

Janet: You know, if there were an organization that was providing the programs we'd like to see for Ian, we'd likely never have got into this. We went in to fill a void. There is no program designed for high-functioning, intelligent, yet socially impaired, or communicatively impaired kids. They aren't there.

Dan: For lower functioning kids, there are programs for them, which grew out of the programs that support Down [syndrome] kids. But for the kids who have some capability, if they're walking and talking pretty well by the end of high school, everyone figures they can live on their own. So off they go, and then, they exhibit several classic profiles: They go to college, they flunk out.... One of our kids was accepted at Berkeley and flunked out, and was bewildered by it. He didn't understand how it happened. He was an incredibly bright kid, and he just couldn't get a handle on it. The impaired social ability absolutely blocked his path to the *normal* way kids get help when they're in school.

The other pattern for these kids is they dive deep into the computer and cannot be pried loose for anything. So, they're 20 years old, they're hanging out in their bedroom, living at their parents' house. They will not get a job, don't want to go to school. That's another "stuck place" that's quite common.

Dan, how did your Asperger's impact your own work life?

Dan: I was always god-awful at the office politics. When my job got to the level where that mattered, that was definitely my glass ceiling. I never got very good at that. 18 >

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 invite him to come to the meeting.”

One of the breakdowns in the educational system, he says, is the “disconnect” between schools and community services. The people planning for transition in the education system rarely interact with the people in support services.

“For a number of complex legal and confidentially issues” he explains, “it’s hard to get everyone connected.... So the system right now really favors the parent advocate, the squeaky wheel. Which I think is a failure of the system. A strong proactive parent can get a lot of things done for their child; but if not, things do slip through the cracks. My best advice is: be as proactive as early as you can in the transition process. I can’t stress that enough.”

• • • •

JANET LAWSON, AN innovative therapist who works with autistic teenagers, also serves on the transition committees of both MAC and Sen. Leno’s taskforce. She’s known locally for creating a unique vocational training program called Autistry Studios.

Lawson, with her husband Dan Swearington and two associates, runs the Autistry program for high-functioning autistic teens and young adults. Currently,

there are four 4-hour workshops for differing age groups each week. The focus is on learning new skills, both practical and social, that will aid them later in the work world. The workshops are designed to be fun—like a freewheeling arts and crafts program—but the real aim is for the youngsters to explore different possibilities and discover new skills they didn’t know they could master. In addition to wood-working, filmmaking, fine arts or graphics, they learn to work alongside others and practice the kind of cooperative “give and take” necessary to succeed in a job. Midway through every workshop is a sit-down meal, which helps participants develop “lunchroom” manners and the social repartee they often lack. (Full disclosure: My daughter attends an Autistry workshop for older ASD adults.)

Lawson says the workshops have proved to be a powerful diagnostic tool for understanding and assessing each student’s needs. “We really see the executive function deficits and strengths. Can they plan but not execute? Do they execute with no planning whatsoever?”

Swearington adds, “We’re able to push them places they wouldn’t go on their own. Get them used to being outside their immediate comfort zone. Because they’re going to have to be able to do that in order to work.”

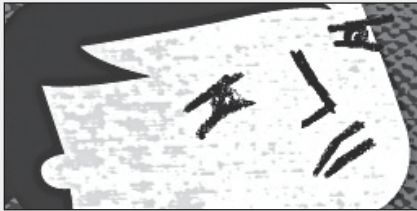
< 14 About a boy

Janet: Dan was director of engineering for Leapfrog [a Bay Area company that designs educational toys and tools]. What was hardest for Dan were the endless meetings. [Dan groans in agreement]

Dan: Once I got into a more boss-like stance, I was all right. I’d simply have nothing but 30-minute meetings. It was only after Ian was diagnosed that I got a glimmer that perhaps that’s what was going on with me. And then I got a lot more comfortable with what I call my “extrovert budget.” I have an amount of time when I can be extroverted, and then I really need to be alone after that. And as long as I’m not over budget, I’m fine. Because then it’s easy to think, “OK, I’ll play to my strengths and try to avoid my weaknesses.” That’s really what everyone does. But in high school, if they find out you’re bad at something, they make you do more of it. As an adult, that’s not how it works. [He laughs] There are lots of things I’m bad at—and I make sure I don’t do them. —Linda Xiques



In addition to her Autistry program, Janet is involved with state Sen. Mark Leno’s Autism Regional Taskforce.



Information and resources

Autistry Studios, www.autistrystudios.com Workshop schedules; new video of workshops in action

AASCEND, www.aascend.net Support group for adults with autism and Asperger's syndrome meets regularly in San Francisco. For details, email info@aascend.net

Marin Autism Collaborative, www.marin-autism.org Autism information and local resources directory.

Matrix Parent Network & Resource Center, www.matrixparents.org A Matrix support group for parents of children and adolescents with autism meets in San Rafael on the third Thursday of each month. Another group for Asperger's and similar profiles meets regularly in Corte Madera. See Matrix website for details.

PROSPECTS, A support group for parents of special needs adults meets every Wednesday, 1-2:30pm at Unity of Marin. For details, email ProspectsMarin@gmail.com

National information: Advancing Futures for Adults with Autism, www.afa-us.org Learn more about the National Town Hall conference and next steps.

Autism Society of America, www.autism-society.org Grassroots organization founded by Dr. Bernard Rimland; offers information and referrals

Autism Speaks, www.autismspeaks.org Autism science and advocacy organization that sponsors research and funds innovative programs.

Easter Seals, www.easterseals.com or www.actforautism.org Access either website to read Easter Seals' "Living with Autism Study." www.noca.easterseals.com provides information on programs in Northern California

National Autism Center, www.nationalautismcenter.org Promotes best practices and reliable information about ASD treatments. Recently issued a comprehensive report based on its National Standards Project.

Organization for Autism Research, researchautism.org Funds research that investigates treatments, educational approaches and statistical aspects of autism. *

Some of the workshop participants have finished high school and are venturing into college classes. "We added college support," says Lawson, "because the kids wanted it. We talk about how they're doing in school, look over their class schedule, do a little tutoring in math or science if they need it, maybe read a chapter together and talk it over. Whatever they need."

The couple was inspired to start the workshops because their own 15-year-old son is autistic. They tried to visualize the kind of help he would need in order to broaden his future.

"We went in to fill a void," says Lawson "We looked around and there is no program designed for high-functioning, intelligent, yet socially impaired, or communicatively impaired kids. They just aren't there."

Autism consultant Kaplan is well aware of the voids and gaps that exist for those with ASD. "Employment? We don't have enough jobs for everyone as it is," she says. "The other thing is housing. We don't have enough housing *anywhere*, it's not just about Marin.... To fill the gap, we need increased private and public funding for ASD housing projects; we need our real estate people and developers to have incentives for building such housing."

It's a tough economic time for education, too. "We need to train more teachers, more speech therapists, more occupational therapists, instructional aides," she says. On a hopeful note, she says that Dominican University, which already has a special education credential program, is planning to add a new ASD credential program in the fall.

It's also important that the wider community knows more about autism, so people with ASD can be accepted and included in recreational activities and community life.

Two years ago, Kaplan started a lecture series to educate the public about autism. "I know a lot of experts," says Kaplan, "people who have done amazing things, great contributors to the field of autism. I asked them to come here and speak.... This is the second year the series has been going on, and I've just finished the lineup for the third year. Parents and professionals can come listen to the state-of-the-art current research on ASD." (Lecture dates are listed on the MAC website.)

Despite today's gaps, Kaplan manages to remain hopeful about the future for people with ASD. She knows the financial crisis will pass eventually and autism research is ongoing.

"I've watched the world of autism change," she says. "We have so much more curriculum and interventions and strategies than we ever had before. So I feel optimistic. We know ASD is treatable, we know that at every level things can get better. Even though there's this huge number of new cases, we also know a great deal now, and we're not going to stop learning." *

Email Linda at linda_xiques@yahoo.com



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