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Special Needs, Special Families

By Lou Fancher



Kent Grelling and Margie Ryerson Photo Lou Fancher

client who had told her typical child, 'Stop complaining, you have a good life.' But siblings of special needs children need to be able to talk about their worries and anxieties too."

Furthermore, she instructed parents to have concrete expectations of their special needs children.

Fighting between siblings is not big news, but when one child is disabled, parents may jump in too early. "Try to let them settle their differences on their own," Ryerson said. "Your special needs child needs to learn how to be strong, to be assertive. The best arena to do that is at home, with their siblings."

True one-on-one time is key to successful parenting in any home, according to Ryerson. "But it's not watching them at piano recitals or at games. You need to get with that child and do something totally devoted to them. That's what they remember later."

If nothing else, Ryerson reminded the audience, siblings of special needs children must have a full life, too. "They need an escape, just like you do," she said.

Kent Grelling, PhD, currently practices in Orinda and serves as the Director of Counseling and Student Support at Bentley School in Oakland. When POISE asked him to speak, he realized that although he knew a great deal about children with autism and related disorders, he didn't know exactly how autism affected marriage.

Popular, main-stream media has picked up on celebrity statements claiming that 90% of marriages with children in the autism spectrum end in divorce. Like any good researcher, Grelling studied the studies. He was surprised at the lack of studies, but referred to research showing only a 1% difference in divorce rates between two-parent homes with ASD children and those with typical children.

Despite the encouragement his comments provided, Grelling was clear that parenting a special needs child is demanding, stressful, and often leaves parents feeling incompetent. "You can get by parenting by the seat of your pants in standard situations," he said, "but when you have a special needs child, everything requires attention and a lot of forethought."

The biggest problem goes against today's you-can-fix-anything message. "You're faced with a problem that actually isn't solvable," Grelling said. And because parents are dealing with an abundance of conflict on a day-to-day basis, he said some marriages do last, but research indicates they are often less than satisfying.

"Two people can be pushed to polar opposites by a problem that really can't be solved," he said. Couples blame each other, attributing the struggle to their partner's alternative style, instead of to the less personal, but still painful reality that life with a special needs child offers no "best way" answers.

Grelling did offer suggestions: be respectful in disputes, find time together without the kids, develop outside interests, share the management and care of your special needs child, and have a sense of humor. While the last instruction is a stretch for couples in deep trouble, Grelling says, "Without it, it's going to be hard to cope."

Close to 40 people gathered at Orinda Books on September 20th to hear two invited guest lecturers speak about the impact of special needs children on marriage, siblings, and family balance.

Parents of Orinda Individuals in Special Education (POISE) sponsored the event. It was the fifth public evening in the organization's 18 month history devoted to the critical issues families with special needs children encounter.

After a brief introduction by Anna Tague, a co-founder and vibrant spokesperson for POISE, Margie Ryerson, a marriage and family therapist in Orinda and Walnut Creek, was the first expert to speak.

Ryerson focused on siblings, placing emphasis on open, honest communication. She encouraged parents to offer repeated, deliberate explanations to their typical children about the experiences the special needs sibling is facing. "Don't wait for your children to approach you to talk," she advised.

Ryerson said "siblings often feel they have to make up for the disabled child's inabilities." Surprising many in the audience, she encouraged complaining. "We all complain," she said. "I had one

Questions at the end of the meeting ranged from how to be fair, in a family situation that is inherently unfair, to when to seek therapy. Ryerson advised not trying to make it fair. "Kids need to know that's impossible," she said. Calling fairness a "false premise," she said cultivating empathy between siblings is the best way to reduce competitive fighting.

Grelling said reducing the contact works too. "If I had to live with my co-workers day in and day out, I'd have trouble, too," he joked. "Give your child a systematic way to deal with the special needs child, that way, you don't have to rush in and solve every drama."

As often happens at POISE events, the Q and A eventually shifted from the guest experts to a more circular, communal conversation centered in the audience. A strong interest in forming sibling support groups arose, and the evening ended with Tague, and many in attendance, promising to continue the discussion through the network that is POISE.

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