

UNEXPECTED JOURNEY – When Special Needs Change Our Course

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Marriage matters...as do all relationships:

- **Imagine five people lying side by side on the waterbed. If one person moves the whole family feels it.**
- **"If there's a special needs child, that bed can really get moving"**

Marriage Matters:

- They confided about the marital strain and the reported 80 percent divorce rate for parents of special-needs children. They discussed the extraordinary expense of raising a developmentally disabled child, which the Centers for Disease Control and Prevention has pegged at about \$1 million over a lifetime.
- Seattle Times, 1/11/05

Marriage Matters

- **The Sunday Times of London puts the divorce rate among parents of children with autism also as high as four out of five marriages.**
- **“Frankly, I am not surprised, given how little assistance many couples receive.”**
 - **Sunday Times (London), 3/5/06**

Marriage Matters:

- Because of these statistics, many are single parents. (Chapters 8-11 in ***UNEXPECTED JOURNEY – When Special Needs Change Our Course*** is important reading for single parents.)
- “For better or worse....”
- NEED the support of others
- Abandoning ship carries a cost, too - stay strong and steady.

Marriage Matters

- **SO-those who ARE married
...don't quit!!**

You can “go the distance” together.

There are rewards along the way

Marriage Matters

God's Blueprint for Marriage

- ❑ **Gen. 2:24 (becoming one) in all ways: emotionally, physically, spiritually...**
- ❑ **To make this Blueprint a reality requires a major commitment to one another and to your vows!**

Build a Strong Marriage

- ❑ **We knew the hard work, the long nights, and the full days we would face, so we simply made a vow to do everything together, no matter how difficult life might get...**

Make Marriage Work...Divide and Conquer!

- **Pamper Your Marriage** – We can't do life as usual for very long without some kind of relief from the pressures of caring for another's full-time needs.
 - Plan intimacy
 - Take time to sit and talk, hold hands, take a walk
 - Laugh together over lighthearted events
 - Have a candlelight dinner once your loved one is in bed
 - Watch a favorite show on a computer laptop/DVD player in bed
 - Kiss for 30 seconds after you pray together in bed at night time. Every night. We dare you.
 - Play a card or board game and laugh.
 - Grocery shop together and make a recipe together.
 - Get coffee.
 - Plan a weekend away when you have opportunity. Just don't forget to come home.

Talk it Out:

- ❑ Write out “care issues”
- ❑ Talk through decisions until mutually coming to an agreement (working through smaller pieces of the decision rather than the big chunk)
- ❑ Give each other full and focused attention
- ❑ Offer solutions without judging or jumping to conclusions
- ❑ Discuss thoughts and feelings don’t yell or argue
- ❑ No “shutting down” – you need each other; don’t walk away!
- ❑ Show respect for each other’s ideas
- ❑ Family Meeting. Include the children. Coordinate your calendars.
- ❑ PLAN

Help Each Other

- **Look for ways**
- **Discuss what works for you and your spouse/helpers**
- **Go the extra mile**
- **Give each other space**
- **Allow each other opportunities to do “their thing” and use their gifts**

Make Your Marriage and Family Your Ministry

- Prioritize your life: God, spouse, family, ministry/ calling, work.

Family Relationships:

- **Extended Family** – Accept help but don't take advantage
- **Siblings** of the one who receives full-time care:

Things That Help

- Protecting siblings rather than overprotecting them (they needed to be treated differently than our child with special needs)
- Giving attention to each child *before* they *needed* it - sharing special times together doing fun things they individually enjoyed – spending quality time together as well as quantity time. Dating your children!
- Providing spiritual training, cultural opportunities, and creative outlets and experiences appropriate to their ages, abilities, gifts, talents, and interests. We supported each other in what each of us enjoyed.
- Valuing each child as special because God made them so wonderfully individual! Recognizing they all had different and special needs. Book recommendation: Charlie Boyd's Different Children, different needs.
- Being proud of each one where they put forth effort – whether they excelled or not.
- Not comparing!
- Helping the children understand that the different seasons of life have different needs and the importance of adjusting to them. The special needs child won't necessarily understand this, but what a valuable lesson for the rest of us! (For example: bike riding as a family lasted only as long the child could fit in the adaptive bike trailer we had.)
- Teaching them that while life isn't always fair, God gives us what we need most, and the help to handle it. Psalm 138:8, "God will accomplish what concerns me."
- Respecting our other children's individual social lives - training them to know how to care for the one with special needs, but never expecting it to be "their job". Getting a caretaker or paying them gave them freedom and responsibility without feeling taken advantage of. It required flexibility and discernment to achieve the outcome we desired, but as we respected their young lives, they became helpful and compassionate woman who love Joey, and ones who have offered to care for him someday.
- Time – one on one and family time.

Rules for All Family Members:

- ❑ Golden Rule in Matthew 7:12, “Therefore, whatever you want others to do for you, do so for them” and Mark 12:31, “You shall love your neighbor as yourself. There is no other commandment greater than these.”
- ❑ Treat each other kindly. We all have value (I Corinthians 10:24, Romans 15:2, Philippians 2:3, 4).
- ❑ Work as TEAM (Together Each Accomplishes More)
- ❑ Talk nicely to each other. Yelling, calling names, and belittling do not constitute kindness. Don’t start trouble. You’ll find what you’re looking for.
- ❑ Be fair. Don’t play favorites.
- ❑ Keep your word. Let your “yes be yes” and your “no be no.” Work together, helping each other whenever possible.
- ❑ Never exclude others.
- ❑ Even when you are tired of listening to your loved one repeat herself or himself for the hundredth (or more) time or she or he has misbehaved or embarrassed you once again, be patient and love the individual through the challenges.

Rules for All Family Members:

- **Family Meetings** – to discuss all aspects of your family life. Always ask the question, “Are we spending enough time with you?”
- **Family Roles and Responsibilities** – so everyone is on the same page. Write out everyone’s roles.
- **Family Goal Planning** – *Balancing the Active Life* and *Get it Together* by Cindi Ferrini are helpful planning resources for the whole family

Others:

- **Friends** – Give them confidence to be friends with the one with special needs - many lack that capability because they “don’t know how”...

Others:

- Introduce the person with special needs. Allow her or him to shake hands if able to do so or let the other person know what is acceptable. “Sally can’t shake your hand, but she’d love a pat on the back.” Instruct them kindly not to shout. Deaf people still won’t hear us if we shout, and a person who is mentally slow won’t understand us any better.
- Find out whether the person with special needs can hear you and speak normally to her or him, looking to the caregiver for clues about how to respond. In addition, if the person with special needs has any kind of auditory stimulus issues (too much noise sets them off and causes them frustration), talking loudly or abruptly could make for a very difficult conversation. Lowering the volume, speed, and tone can help. Loud noises can distract a person from concentrating. Wait until he or she is calm before continuing the conversation.

Others:

- Ask about the disability if appropriate. Give the person with the disability the freedom to talk about it if desired, and the freedom not to. Using a word like see with a blind person or hear with a deaf person or walk or run with someone in a wheelchair is usually nothing to worry about if you are using it in general conversation and not a hurtful way!
Example: If we say to someone who is blind, “I see” for “I understand,” that is normal conversation. If we say in frustration, “Don’t you SEE?” it lacks sensitivity and could be hurtful. If we can think ahead fast enough to avoid these words, we are better off. The bottom line is sensitivity.

Others:

- It's OK to ask people with special needs to repeat themselves. If we have to ask too many times, though, seeking the caregiver's assistance can ease an awkward situation. The worst tactic is dropping the subject, especially if the person is really trying to make something clear. At times, however, the severity of lack of verbal skills may necessitate our gently moving the subject into another direction without disregarding the individual's ideas.
- Keeping conversation short and simple is a good idea if it becomes difficult. Always end the conversation politely.
- Ask one question at a time and wait patiently for the individual to answer. Don't worry if waiting a few seconds is a little uncomfortable.

Others:

- ❑ When speaking to a deaf person who has an interpreter, make eye contact with the deaf person.
- ❑ When conversing with a blind person, do not “make friends” with her or his Seeing Eye dog. Do not pet, offer a treat, or otherwise distract the dog from the job for which it has been trained.
- ❑ If a person is in a wheelchair, stoop down to talk to them face to face. Remember that being in a wheelchair doesn’t mean she or he can’t talk or understand.
- ❑ Stay positive and pleasant.
- ❑ Don’t correct the person unless you are sure they understand what you are trying to say and what your motivation is for the correction.

Teachers, Aides, Administrators:

- ❑ As a parent....when you don't know what to do, ask for help!
- ❑ Don't deny that your child has special needs.
- ❑ Make your child your priority. Advocate for him or her.
- ❑ Your school system should give you the information on laws every time you have an IEP conference for your child. Be sure to read and understand this information before confronting people about things you want for your child.
- ❑ When expressing what you want, be firm, helpful, kind, and polite.
- ❑ Be realistic about the needs and abilities of your child.

Teachers, Aides, Administrators

- ❑ Don't always expect to get your own way. Be flexible.
- ❑ When a problem arises, talk to the teacher first. If you get no results, consult the head of the building or district special education department or principal; and if you still get no results, speak to the superintendent. Don't start at the top. You'll burn bridges that way, and they won't like seeing you coming.
- ❑ Don't demand. Ask how you can help and be part of the process and solution. Demanding versus helping are two different approaches. One works.
- ❑ Offer to help in classrooms. (We volunteered to help in art and basic computer skills class, sat in on speech therapies, and so forth. It was a great learning tool for us as well as seeing what our child was learning and who was in his life!)
- ❑ When you don't know what to do, ask for help. Talk to counselors, other teachers and parents who can help you to sort things out and set you in the right direction.
- ❑ Get involved in your child's IEP, special education meetings, committees, and seminars. Far too many parents don't do a thing—unbelievably!

Teachers, Aides, Administrators:

- ❑ Encourage, thank, and appreciate all the people who work with your child. Send notes to express those feelings. An occasional small, inexpensive gift (e.g., stickers to use in class) that conveys your feelings is a great way to establish yourself as one who is caring and kind. When you need to meet and discuss something that is “difficult,” they know you are approachable, logical, and will listen to all the facts.
- ❑ Remember to also show appreciation to the aides, bus drivers, therapists, and administrators who educate and care for your child. Be the same person to them that you want them to be for your child. They are all important in the care and educational concerns of your child.
- ❑ We had a notebook that was sent between home and school to keep up good communication from teacher to parent and vice versa. It reduced phone calls and unnecessary meetings.

Churches...Finding a Place

<http://www.keyministry.org/>

Key Ministry-A Church for Every Child

<http://www.joniandfriends.org/church-relations/>

□ **Through the Roof Ministries**

Issues:

- ❑ Isolation - No one says you're excluded, but by NOT being included, but you feel like it.
- ❑ Paperwork – mastering it
- ❑ What others say
- ❑ Behavioral Issues
- ❑ Rest
- ❑ Questions and Answers

Articles by and Interviews with Joe and Cindi:

- Familylife Today – 3 days of programming called Unexpected Journey from their book (2/09) UNEXPECTED JOURNEY – WHEN SPECIAL NEEDS CHANGE OUR COURSE
- June 29, 2009 Dennis Rainey and Bob Lepine interview Joe and Cindi on FAMILYLIFE today radio. Topic: Facing a Painful Reality:
<http://www.familylife.com/site/apps/nlnet/content3.aspx?c=dnJHKLNNFoG&b=3789887&ct=7133605>
- June 30, 2009 Dennis Rainey and Bob Lepine of FAMILYLIFE TODAY interview Joe and Cindi. The topic is: Embracing Life's Changes:
<http://www.familylife.com/site/apps/nlnet/content3.aspx?c=dnJHKLNNFoG&b=3781143&ct=7048085>
- July 1, 2009 Dennis Rainey and Bob Lepine of FAMILYLIFE TODAY interview Joe and Cindi on the topic, "Love: A Day to Day Assignment":
<http://www.familylife.com/site/apps/nlnet/content3.aspx?c=dnJHKLNNFoG&b=3781143&ct=7133605>

Online Broadcasts:

- Start Your Family: Becoming Parents of a Special Needs Child: (An interview with the Ferrini's)

<http://www.startyourfamily.com/2009/05/becoming-parents-of-a-special-needs-child.html>

- Need Project: - UNEXPECTED JOURNEY: (Ministry NEED PROJECT)

<http://www.needproject.org/castspodcast1033.mp3>

Focus on the Family

- FOCUS ON THE FAMILY –Special Needs and Marriage – module of 1 overview and 6 articles in a series for their on-line magazine:
http://www.focusonthefamily.com/marriage/marriage_challenges/special-needs-and-marriage.aspx
- Excerpt Article from UNEXPECTED JOURNEY – WHEN SPECIAL NEEDS CHANGE OUR COURSE - one article in a series:
http://www.focusonthefamily.com/parentingparenting_challenges/parenting_a_special_needs_child.aspx

Focus on the Family:

- RADIO: Focus on the Family interview taped July 20, 2011 for airing January 2012.

Books:

Balancing the Active Life - an interactive Bible study for anyone of any age - the goal of this 13-week study is to challenge and encourage the participant to prioritize the activities they believe are the most important in their life, with Christ being the center and the focus of all that they do.

Get it Together - an organizational planner

'Tis the Season - a Christmas planner to keep the holiday less stressful and more meaningful

Unexpected Journey, When Special Needs Change Our Course – Dr. Joe and Cindi share their journey of caring for their son with special needs and their parents with Alzheimer's.

Website

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