

# Married & Unmarried.... with Fragile X Children



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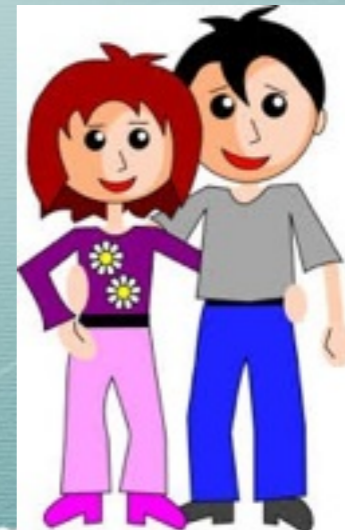


# Qualities of Healthy Marriages (Gottman)

- Happily married couples behave like good friends.
- Happily married couples handle their conflicts in gentle, positive ways

# In Healthy Marriages, Partners:

- feel connected through time, affection, verbal and physical intimacy
- have good communication and conflict resolution skills
- have tolerance and respect for each other's differences
- share a fair distribution of power and responsibilities
- feel like a team and are able to adapt to changing circumstances
- Have a sense of their individuality and the “we-ness” of the relationship
- are committed to the marriage



# When Baby Arrives:



## 1<sup>st</sup> critical transition:

- What happens when baby assumes center stage?
- Does husband feel the transformation of parenthood or does he feel left behind?
- What happens when one parent (usually Mom) becomes the “expert” in taking care of the child?

- **2<sup>nd</sup> Critical Transition**

After the initial stages of infancy, do the partners reorganize their relationship so that the “marriage” has a place outside of their roles as parents?



# What Happens when a Child Has Special Needs?

“I would compare the experience of having a disabled child to the experience of parenting during the first eight weeks of an infant’s life – intense, exhausting, you are always on duty (vigilant). All other aspects of your life fade to the background, and you question yourself and your decision. It’s that intense, and the difference goes on for years.”

From [Married with Special Needs Children](#)  
By Marshak and Prezant





# When a Child Has Fragile X

- **1<sup>st</sup> critical transition:**

How does each partner move through the grieving process?

- **2nd critical transition:**

How do the partners, both as individual as a couple, integrate the experience of disability in their family so that the “marriage” has a place outside of their roles as “special needs parents?”

# Individual Challenges

- **Managing grief**
- **Maintaining perspective**
- **Protecting a corner of life for yourself**
- **Finding sources of strength**
- **Coping with uncertainty and fears of future**
- **Managing guilt, fear and shame**
- **Finding healthy support outside of the marriage**
- **Finding meaning in the disability experience**

# Challenges for Couples

- Establishing or reestablishing a bond despite the tendency of a child's disability to be "all encompassing."
- Accepting differences in emotional reactions to disability
- Adjusting to roles that meet family needs in a manner that feels essentially fair and does not breed resentment
- Retaining nuances of romance and the ability to see each other as more than "parenting partners"

# Couples' Challenges

- **Developing a creative vision for the future**
- **Adjusting to roles that meet family needs in a manner that feels essentially fair and does not breed resentment**
- **Coping with financial strains**
- **Negotiating division of labor and degrees of involvement**

# Couples' Challenges

- Feeling isolated from family and friends
- Coping with lack of time together and alone
- Managing emotional differences in grieving and coping styles



# “Gifts” of Having a Fragile X Child

- Feelings of having a special purpose
- Re-ordering of priorities --a sense of knowing “what’s important”
- A sense of gratitude for the “smallest” accomplishments of your child
- Feeling of being part of a team

# Keeping Connected



- ◉ Time alone together
- ◉ Express appreciation sincerely and often
- ◉ Share laughter; find humor in every day things
- ◉ Praise frequently; criticize rarely
- ◉ Respect each other's different ways of dealing with your child's disabilities
- ◉ Accept each other's strengths and limitations

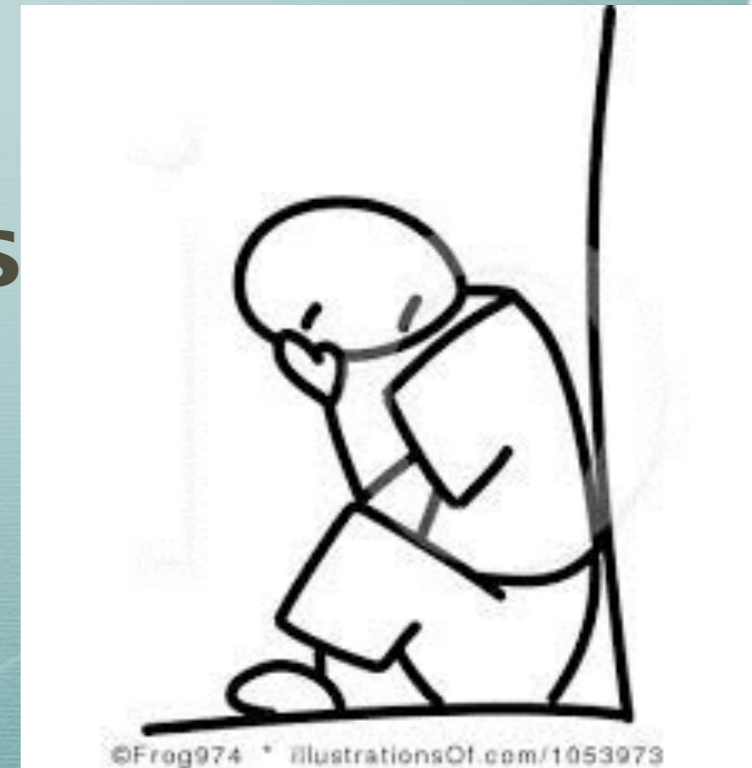
# Relationship-Enhancing Behaviors

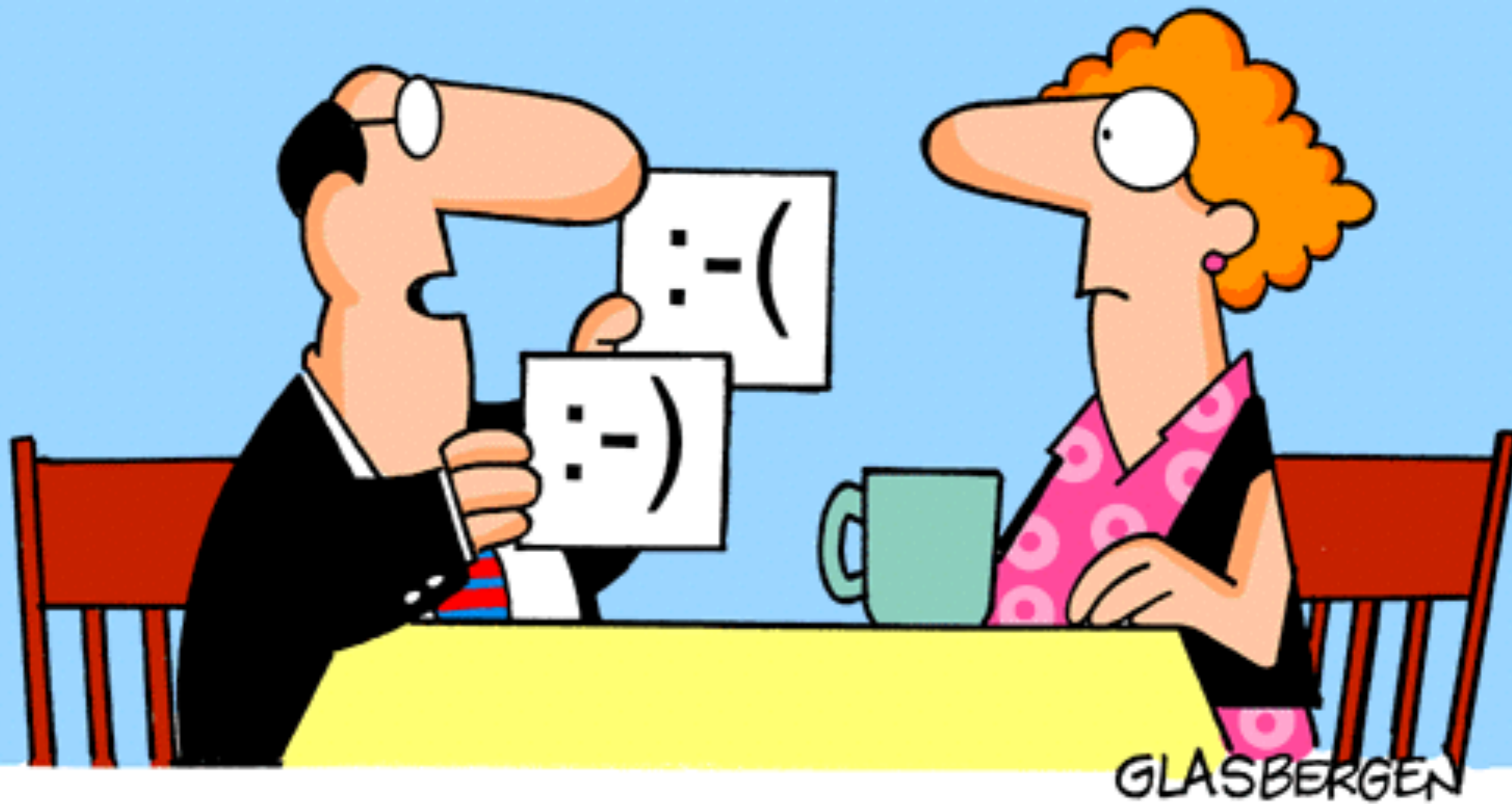
- Softened start-up
- Turning toward your partner
- Repairing the rupture
- Accepting influence from your partner
- Using high ratio of praise to criticism



# Signs that a family member needs help:

- Increased or excessive alcohol or drug use
- Other addictive behavior
- Significant under or overeating
- Depression
- Anger outbursts
- Threat of harm to self or others





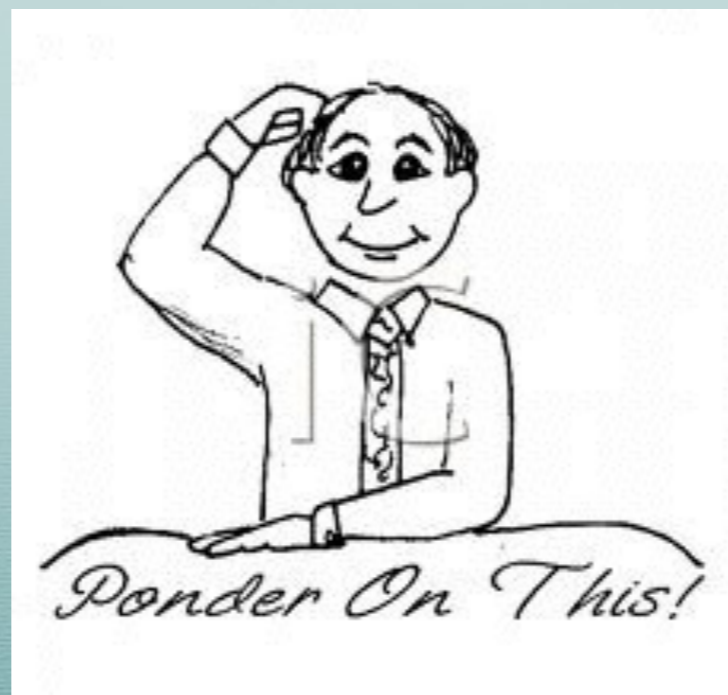
**“You always complain that I don’t know how to show my emotions, so I made these signs.”**

# Understanding Each Other

- For men:

What is hard about being the mother of a child with Fragile X Syndrome?

What does my wife/partner need from me?



- **For women:**

What is hard about being the father of a child with Fragile X Syndrome?

What does my husband/partner need from me?



# Couple visioning

- What is my vision about what my relationship could be?
- What one step can I take to move toward making that vision a reality?



# When Parents Are No Longer Together



# Reducing the Negative Impact of Divorce on Children

- Do not expose the children to the conflict between you and your ex.
- Avoid having your children emotionally “parent “ you
- Provide reassurance that you are fine.
- Do not appear visibly upset in front of the children.



- Do not confide your feelings about the divorce or you expose to them.
- Find other sources of support
- Encourage your children to see their friends
- Establish as much normality as possible
- Refrain from bad-mouthing other parent to or in front of children





- If possible, both parents maintain contact with therapists, teachers, and doctors.
- Put children first, over any concerns about fairness or personal resentment
- Keep communication between parents brief and business-like
- Keep movement between homes consistent.



# Resources

Married with Special-Needs Children by Laura Marshak and Fran Prezant

Mom's House, Dad's House by Isolina Ricci