

LITTLE CHAMPIONS.... BIG DREAMS!

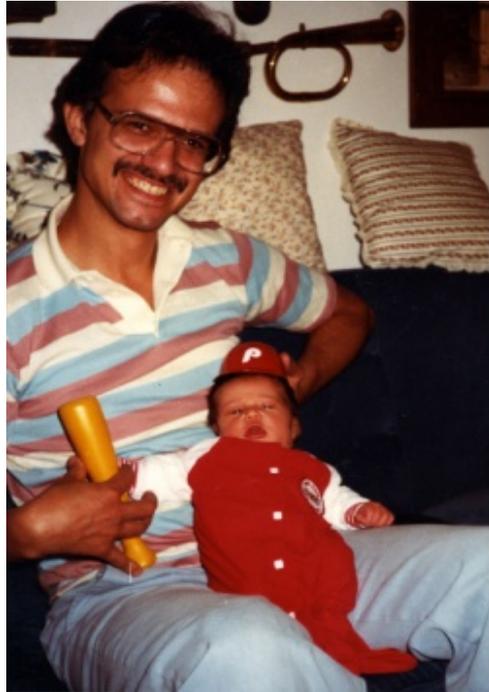
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UNEXPECTED JOURNEY-WHEN SPECIAL NEEDS
CHANGE OUR COURSE

By Joe and Cindi Ferrini

Little Champion – Big Dreams



Introductory story – little girl taking a piano lesson
(page 13 of UNEXPECTED JOURNEY- When Special Needs Change our Course)

THE DIAGNOSIS – Dreams Shattered

- Birth
- Not hitting milestones
- Joe: noticed his eyes
- Cindi: noticed his head size and lack of muscle tone
- NOT the job I signed up for!
- Doctor visits/DX: “Developmentally Delayed” – “He’ll catch us eventually....”
- EVENTUALLY gaps get wider and wider as progress in age
 - Huge motor and fine motor skill delays
 - Mentally challenged
 - Epilepsy
 - Severe and less severe allergies
- PROFESSIONALS KNOW HOW TO DIAGNOSE AND HOW THAT DIAGNOSIS BEHAVES IN THE GENERAL POPULATION, BUT ONLY THE PARENTS KNOW HOW A DIAGNOSIS BEHAVES IN THEIR CHILD.
- Professionals – Take time to speak to the pain before generalities, statistics, etc.
- Take TIME to connect as professional to parent.

THE BLAME GAME –

Looking for ONE place to point a finger

- How easy for parents to blame:
 - 1- Each other: 80-85% divorce rate
 - Yet often those who get through this initial “place/stage” have stronger marriages than others!
 - 2- The doctors or other health care professionals
 - Yet we can get to a point that they are needed greatly and great relationships are often forged from initial “difficulties and diagnosis”
 - 3- Ourselves
 - What ONE thing can “I” blame? (as a parent - we ALL look for it!)
 - Own up to it if there IS a reason
- “Because of the drugs I my past and other lifestyle issues, I had to own up to the fact that some of what I was dealing with in my son’s special needs was a result of my past. It was hard to admit, but when I did, I was finally able to move on, get him the kind of help he needed, and deal with my own issues. The consequences of life are often difficult but change seldom happens without ownership of our part in those consequences.” (pg. 65 of UNEXPECTED JOURNEY, written by a contributor)

MOVE ON....Sometimes “life” just happens....

- Life Changes:
 - On a different course than ever dreamed or expected
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- Life Changed:
 - Lifestyle
 - Dreams
 - Finances
 - Time
 - Energy
 - Plans
- Often DISAPPOINTMENT sets in: our opportunity to STOP, LOOK, LISTEN!

MOVE ON....Sometimes “life” just happens....

- From blaming we begin asking questions that will move us forward:
- Can YOU fix it?
 - Tests
 - Poking
 - Prodding
 - Machines
 - Needles
 - Noises
 - **STOP!!!! NO MORE TESTS!!!!!!!!!!!!!!**
- Can we have other (healthy) children someday?
- What will my child be able to do someday?
- Will we be able to afford all the care our child will need?
- How will I plan for my future and the future of my child?
(From pages 37-38 of UNEXPECTED JOURNEY)
- Changes = UNDER CONSTRUCTION!

MOVE ON....Sometimes “life” just happens....

- With purpose – move on:
- Quote from page 42 of UNEXPECTED JOURNEY, “We had no ideas that we would have new great expectations to learn how to deal with behavior.....”
- Expect and plan to go through the 5 Stages of Grief (Elizabeth Kubler Ross)
 - Denial
 - Anger – the danger
 - Bargaining
 - Depression
 - Acceptance – the key



MOVE ON....Sometimes “life” just happens....

- In ACCEPTANCE is where we will best SETTLE in and GROW (personally)
- There are NO QUICK fixes:
 - Take time to tweak
 - Take time to change
 - Take time to change even more!
- NEW NORMAL – wrap your mind around it!
- People you’ll meet:
 - Build don’t burn bridges
 - They are there to help
 - Let them know when you need more
 - Let them know when you’re pleased
 - Say thank you
 - Star off with open and transparent (but gentle) communication
- Be a part of the SOLUTIONS not a part of the PROBLEMS
- EVERYTHING a professional AND parent is asked to do is difficult!
- But we will have NO REGRETS if we choose not what is
EASY-COMFORTABLE -FUN.....but what is RIGHT!

HOW DIFFERENT IS IT?

- It's like Emily Perl Kingsley 1987 "WELCOME TO HOLLAND"
- It's like a vending machine: money in, wrong item pops out
- It's like the Grand Canyon: our analogy! (Page 117, UNEXPECTED JOURNEY)
- It's so different, that even if you are a professional, *unless you have a child with special needs...* you can't fathom it.
- **DIFFERENCES** (in a nutshell)
 - Dreams we had to let die
 - Help – we need SO MUCH help
 - Isolation – from family and friends and sometimes our mate
 - Lack of Freedom – for all
 - Social Changes – work, family, friends, church, hobbies, etc.
 - Impact on the family - marriages, siblings, extended, etc.
 - Onlookers and others: what others see is not what we see!
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HOW DIFFERENT IS IT?

- FRUSTRATIONS

- What others say and do:

- “I thought you were bigger than that!”
- “My child has taken 2 weeks to potty train.”
- “You must be a special person to be a parent of a child with special needs.”
- “I could NEVER do what you’re doing.” (Professionals and parents alike!)

- What we say and do (Professionals AND parents):

- “I need more rest!”
- “I can’t do this anymore!”
- “I want to quit!”
- “I’m tired of what others say.”
- “This is too hard!”

HOW DIFFERENT IS IT?

- WE HAVE DECISIONS TO MAKE! We have choices!
- NEW NORMAL, REALITY AND PERSPECTIVE:
- NEW NORMAL –
- NEW REALITY
- NEW PERSPECTIVE – HUMOR



HOW DIFFERENT IS IT?

- REALITIES:
Life is going to be different – Trial to Triumph!
- It's always changing – Change is the only thing that doesn't change! - So much work!
-
- IT IS OK TO BE HUMAN - you will be frustrated/there will be meltdowns
- Learn WHO wants to listen – don't tell everyone everything/not everyone cares
- Admit when you're envious or jealous – then show joy for others!
- Admit when you need help
- Care for yourself
- Keep good recordings of doctor visits, IEP's, appointments (BIG BOOK!)

- JOURNAL your story – On Facebook: **Joey Stories (as told by Mom)**
- TAKE the frustrations and make DECISIONS to make it work!
- PAIN, CHALLENGE and CRISIS build character if you LET it!



HOW DIFFERENT IS IT?

- DATES with my spouse:
- Vacations/ travel: Needs a lot of help/change, but we're still getting away!
- Loneliness: Invite people over!
- Become an expert on the one (or those) you care for!
- Find a hobby for to enjoy
- MENTOR younger families
- HAVE FUN! LAUGH! HUMOR



HOW DIFFERENT IS IT?

- This UJ is a long haul!
- Progress is slow –
Professionals help parents
see the progress we don't
always see and parents
appreciate professionals
who help!

