

The Evolution of a Special Needs Parent



After talking to parent after parent and hearing about where they feel stuck, I created “The Evolution of a Special Needs Parent”. This is a five-stage framework that identifies common experiences and action steps for growth in each of the five stages. My invitation to you is that you use this framework to self-evaluate and assess where you are at in your journey and use it to inspire your personal development, growth, and reinvention.

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Stunned Survival

YOUR EXPERIENCE:

- Entirely focused on intaking the new language, new diagnosis
- Emotions numb and unfeeling; Survival mode: fight, flight, and freeze
- Tunnel vision: focused on caring for your child, only putting minimal effort in other areas of life.
- Receiving lots of community support: Friends and family rally and makes lots of offers to help.
- Thinking of day-to-day needs, not spending a lot of energy thinking about the future.

ACTIONS FOR EVOLUTION:

- Adjust your work schedule or quit your job, rearrange child care and schedule, for life's new challenges.
- Learn, research, and find your child the help they need.
- Accept support from your family and friends. Set up community supports as they are available.
- Shift from the sprint to the marathon: start to focus on your new life rather than focus on the newness of the diagnosis or needs.

PHASE 2

Stabilized, Yet Self-Sacrificing

YOUR EXPERIENCE:

- You've stabilized and have established routines and familiarity, the newness has worn off.
- All IN for healing your child, even at the expense of completely neglecting yourself.
- "If, then" thinking. If my child____, then _____. If your child walks, you will feel peace.
- Control is a major source of power, you attempt to control your environment to compensate for the loss of control.
- Question self, trust others more than self.

ACTIONS FOR EVOLUTION:

- Recognize this self-sacrificing behavior and acknowledge that it's not sustainable.
- Take back a little energy or time for your self-care, even if you feel a little lost or don't know what will help.
- Separate from your old community, and pull back from relationships. Find your new community.
- Reflect on the disconnect from your internal state, and be open to exploring what you've stuffed to survive.
- Notice and acknowledge the internal chaos.

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The Rebellion

(aka Alone and Afraid)

YOUR EXPERIENCE:

- Feel really alone, don't have the community you want and miss.
- People look at you and think you have it all together, but inside you are somebody you don't recognize.
- Constantly feel overwhelmed, don't know how to manage all that you think you need to do.
- Exhausted: You've given it all, yet you haven't been able to get your life back. You start to feel desperate because you can't imagine living like this forever.
- Often critical of self and judge yourself harshly.

ACTIONS FOR EVOLUTION:

- Identifying that what is missing is effective coping skills.
- Look for and find help. Decide you will do something about this--you can't stay here.
- Find your voice, shift from focusing on what the experts say, and learn to lean on your own wisdom.
- Re-balance your life and shift from giving 110% to your child to giving intentionally.
- Invest time, energy, and sometimes money to get support.

PHASE 4

The Restoration

(aka Calm the Chaos)

YOUR EXPERIENCE:

- Experience acceptance for your child, their diagnosis, the unresolved challenges, and yourself.
- Reinvent your identity. Feel invigorated about life again.
- A noticeable shift in your inner chaos. Rather than feeling helpless and hopeless, you start to feel empowered and confident.
- Restored relationship with yourself, you bring yourself kindness and approach your life with curiosity.

ACTIONS FOR EVOLUTION:

- Step up and identify as a leader who leads your life and your family. Making powerful requests and confident decisions.
- Consistently practices the skill of processing deep emotions like anger, grief, resentment, and sadness.
- Identify and give yourself what you need.
- Actively cultivate joy through intentional play.
- Ask for and receive support.
- Create an expanded network of support for all areas of your life.

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PHASE 5

Power, Peace & Possibility

YOUR EXPERIENCE:

- You feel in control of your life like you have the ability to meet your needs, even in very hard circumstances.
- You process deep and powerful emotions, continually building the belief that you are enough in all situations.
- Embracing that life is joy and sorrow.
- You dream, play, and feel fully alive.
- Have a deep and well-connected community.

ACTIONS FOR EVOLUTION:

- Continually evolve through the stages, deepening and growing.
- Identify areas you don't feel empowered and use tools to shift out of the disempowered place.
- Serve others: Use your giftings and passions to serve your family, community, and beyond.
- Constantly expand capacity, especially in love and vulnerability.

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