

Post-Traumatic Growth in Parents of Children with Autism: A training with specific strategies

By Kirsten Richburg



Logo for Growing Kind Minds LLC. (source: <https://growingkindminds.com/>).

Post-traumatic growth (PTG) refers to positive changes that can occur after an individual faces a traumatic event. When this term is mentioned in connection with parents with children with autism, given the stresses of that situation, one may not immediately understand the association. A training course made this connection clear and hopeful by providing helpful techniques to help such parents cope in a healthy and thriving way.

The term Autism Spectrum Disorder (ASD) describes children and adults with developmental deficits characterized by restrictive and repetitive behaviors, emotions, and thoughts that impact social communication and interactions, with variabilities for each individual. Such individuals typically require additional support to help them communicate and interact with the world around them. Since parents -- and those responsible for the care of those with ASD -- are responsible for the holistic environment in which the child is raised, they need to be emotionally prepared as well as physically capable. However, these caregivers' needs and challenges tend to be overlooked. If caregivers' mental health and well-being go unnoticed and unheeded, it can lead to detrimental effects on the caregiver and the child.

To address these concerns, the Hudson Valley Professional Development held an online training course on December 15, 2022, entitled *Post-Traumatic Growth In Parents of Children with Autism Spectrum Disorders*. This four-hour training cost USD\$120 and offered 4 CEs (continuing education credits) for professionals interested in furthering their education in Applied Behavior Analysis (ABA) and family therapy, including for varied New York State Licensed professionals, e.g. Mental Health Counselors, Licensed Master Social Workers, Licensed Clinical Social Workers, Licensed Marriage and Family Therapists, Licensed Creative Arts Therapists, psychologists, and psychoanalysts. The course was taught by Dr. Victoria Grinman, who highlighted the struggles and challenges faced by parents of children with ASD who were identified, evaluated, treated and researched by her in her clinical practice. The training further included how parents' experiences their child's development. Upon completion of the course, attendees received the CE credits and a certificate of completion.

The author of this paper notes that this topic relates to the Sustainable Development Goals of the UN 2030 Agenda in terms of SDG 3 (Good Health and Well-Being) and SDG 10 (Reduced Inequalities), which cover, respectively, the mental and physical health of all individuals, which includes parents of and children with autism, and the inequalities that these two generations face in terms of opportunity and education. This relationship with the UN Agenda is important since this paper is related to my participation and requirements in the course on “Psychology and the United Nations” given at Columbia University Teachers College by Professor Dr. Judy Kuriansky, who represents NGOs at the UN and has 20-year experience advocating at the UN about mental health and well-being.

Dr. Grinman, referred to as the “parent whisperer,” a person in whom parents can confide and can use as a resource for information and relief, has decades of experience as a dual-licensed psychologist and aromatherapist, is a clinical social worker in New York and Massachusetts, and is the founder of Growing Kind Minds LLC, a private practice and global community platform that helps individuals achieve joy and overcome trauma-related challenges (Growing Kind Minds, 2022). Her aim of this training was to offer an understanding of the “multilayered compounding parenthood experience of parents of children with ASD.” The 38 professionals in attendance were given information on how these parents uniquely cope, the markers of post-traumatic growth (PTG), and how to help facilitate PTG in this population. Dr. Grinman also presented some of her most recent research on this topic and shared her insights from her ongoing qualitative study examining the PTG experience of parents of children with ASD.



Dr. Victoria Grinman (<https://growingkindminds.com/>, 2020).

Posttraumatic Growth (PTG)

Psychological trauma occurs when individuals are unable to naturally cope or navigate an overwhelming and unforeseen event or circumstance (Calhoun & Tedeschi, 1995). In contrast, PTG represents the positive psychological change in individuals who have suffered from some trauma; a concept developed and promoted by Calhoun & Tedeschi (1995). According to Calhoun & Tedeschi (1996), individuals who have achieved PTG are characterized by five factors. They:

- 1) find they relate more to others with greater compassion
- 2) have discovered new possibilities in life (new roles and people)
- 3) appreciate their own personal strengths
- 4) undergo a spiritual or belief system change (connection to a greater good)
- 5) have a deeper appreciation of life and its meaning.

PTG is measurable through the PTG Inventory (PTGI), a 21-item self-report scale used to help clinicians assess for growth in these five domains. The 21 statements listed in the questionnaire are rated on a 5-point scale, with 0 indicating the client "did not experience this change as a result of [their] crisis" and 5 showing the client "experienced this change to a very great degree as a result of [their crisis]" (Calhoun & Tedeschi, 1995). The scores are added to provide information on any growth the client has experienced since the traumatic occurrence.

Post Traumatic Growth Inventory

Client Name: _____ Today's Date: _____

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.

- 0 = I did not experience this change as a result of my crisis.*
- 1 = I experienced this change to a very small degree as a result of my crisis.*
- 2 = I experienced this change to a small degree as a result of my crisis.*
- 3 = I experienced this change to a moderate degree as a result of my crisis.*
- 4 = I experienced this change to a great degree as a result of my crisis.*
- 5 = I experienced this change to a very great degree as a result of my crisis.*

Possible Areas of Growth and Change	0	1	2	3	4	5
1. I changed my priorities about what is important in life.						
2. I have a greater appreciation for the value of my own life.						
3. I developed new interests.						
4. I have a greater feeling of self-reliance.						
5. I have a better understanding of spiritual matters.						
6. I more clearly see that I can count on people in times of trouble.						
7. I established a new path for my life.						
8. I have a greater sense of closeness with others.						
9. I am more willing to express my emotions.						
10. I know better that I can handle difficulties.						
11. I am able to do better things with my life.						
12. I am better able to accept the way things work out.						
13. I can better appreciate each day.						
14. New opportunities are available which wouldn't have been otherwise.						
15. I have more compassion for others.						
16. I put more effort into my relationships.						
17. I am more likely to try to change things which need changing.						
18. I have a stronger religious faith.						
19. I discovered that I'm stronger than I thought I was.						
20. I learned a great deal about how wonderful people are.						
21. I better accept needing others.						

Post-traumatic Growth Inventory (source: Calhoun & Tedeschi, 1999).

How does PTG relate to parents of children with ASD?

In the training session, Dr. Grinman made a point of distinguishing between parenthood and parenting. Parenthood is “a state of being a mother or father, with all of its positive and negative experiences related to raising a child, and all the constant changes and boundaries established,” while parenting is more simply described as “the art of raising that child.”

In the early stages of her research, when Dr. Grinman asked parents of children with ASD to describe their experiences with parenthood, she found that parents would often “talk exclusively about their child’s experiences, what the child might think or feel,” neglecting their own experience. Raising a child on the spectrum in a connected and balanced environment makes it more common – understandably – that parents would describe their experiences through their child, who is the main focal point of their lives. But Dr. Grinman’s research was intended to get th parents to speak about themselves, and therefore to separate the parent’s own experiences from that of their child, and to delve into the effects their child’s condition has on the parent’s mental and physical state.

ASD is a complex developmental and neurological disability that appears in the first few years of a child’s life. Thus, parenting such a child can be very challenging. Parents of children invariably have assumptions about how their parenthood journey will be and how their children will develop, expecting a “normal” child. Thus, when professionals tell them that their child is on the Spectrum, this can be traumatic news, which significantly shocks parents’ assumptions and expectations that even get “demolished by the stark reality of this condition.” The new, unexpected situation and required adjustment trigger a range of emotions, including confusion, frustration, insecurity, feeling overwhelmed, and unable to cope with this new reality. According to Dr. Grinman’s qualitative study and research on parents of children with ASD, the source of parental trauma is not necessarily the diagnosis itself but the effects of the diagnosis on their personal and professional lives going forward, as they immediately know they must make accommodations and adjustments for the child and themselves.

The nature and also the point of trauma varies from parent to parent, meaning that trauma can develop immediately upon knowing the child's condition, or can emerge later in the parenthood journey. Also, the behavioral issues of the child can manifest early or later in the child's development, causing parents to drastically change their life. Also, in some situations, the stress of raising a child with ASD can lead to such extreme parental discord that ends in divorce. These varied situations and reactions are important when determining how best to help parents respond to this trauma and to help them build resilience, recover, and eventually thrive in their new reality.

As Dr. Grinman points out, PTG for parents of children with ASD “happens in the context of, and due to, the struggle of processing pain and loss.” It is the reaction to the trauma, the “spectrum between emphasizing loss only to reassessing the meaning of what’s present and possible.” It is the “experience of growth or benefits that an individual receives due to the post-traumatic struggle.

How parents of children with ASD can cope

Parents of children with ASD typically experience stress in parenthood to varying degrees, which can be multilayered and compounding. Overall, parents have diverse and specific challenges and stressors that depend on the severity of their child's symptoms, their immediate environment, and the parents' resources to cope with the child's condition.

According to Dr. Grinman, the parenthood journey is comprised of three layers. The first layer is parenthood in general and all those common challenges. The second layer involves coming to terms with having a child with a chronic disability that requires additional and unique support/resources. The final layer deals with societal judgments and potential ostracization by the community, other family members, and often other parents who do not have children with ASD or understand the neurological disorder. Parents at the third stage tend to experience what Dr. Grinman calls "ambiguous loss," which is the feeling of loss experienced when parents find out they do not have the child they expected, and must come to terms with the realization that they will be dealing with many unknowns.

Despite the multilayered stress and negative outcomes that parents of a child with ASD may experience, there can be benefits and growth produced in the journey of parenthood. "These benefits reflect five domains of PTG; new possibilities, appreciation of life, personal strength, relating to others, and spiritual change."

Three strategies/activities for clinicians helping to facilitate PTG with parents of children with ASD, were introduced by Dr. Grinman.

1) One strategy is a two-handed writing activity in which parents use white, non-lined paper (to give the parent freedom and less restrictive access to the page), colored pens/pencils, and a timer to engage in a freestyle writing exercise. During this exercise, the clinician invites the parent to converse with two different parts of themselves: one part feels alone and unable to rely/lean on anyone for support (the "traumatized" part), and the other "wise" part of themselves can focus on growth. The parent is instructed to divide the paper in half and choose a different colored pen/pencil to represent both sides and decide which hand will describe each part (i.e., whether the dominant hand will represent the wise part or the part feeling inadequate). The parent then begins writing, and alternates between the two halves of the paper. The "traumatized part" can write whatever thoughts or feelings need to be expressed, while the "wise" part identifies how they can cope with their new reality, for example, including others they can lean on. If, during the exercise, the parent is feeling ambivalent or "stuck," they are instructed to let both voices be heard by using a stream of consciousness, to let the ideas and thoughts come out naturally and sort them out later. At the end of the activity, the parent and clinician review and reflect on everything the parent wrote down.

2) The second strategy is aimed at helping parents change their outlook on parenthood and is based on a "dialectical thinking collage" meant to facilitate new possibilities. In the activity, parents select paper, colored utensils, and other art supplies, such as magazine pictures or images, to represent how they feel. This activity can also be done online via PowerPoint, SmartArt, or Google Workspace, whereby, instead of using a sheet of paper, the software would act as the blank canvas on which pictures or images will be placed. After selecting a canvas, the parents are asked to divide the canvas in half; one side is supposed to represent/depict the now

and past, while the other side represents/shows the future. The parents should select images that portray aspects of their past and present life, for example, hobbies, sports they played when they were younger, or pictures related to their current profession or status. The images reflecting the future should portray the parents' hopes and desires; how they envision their lives going forward. When looking at both parts of this canvas, the images can often reflect contradictory representations - which shows the varied feelings that can exist within the same space, and normalizes them. Creating this collage helps parents see the challenges they are facing. Through discussions with the clinician, in which the representations are dissected and evaluated, they can work through these challenges to create a functional life where they can still find joy amongst the stress they are undergoing. After utilizing this activity with patients in her practice, Dr. Grinman noted that some parents were observed to have developed new interests "that related to having a child with ASD, took healthy risks, and created new opportunities for themselves that were more aligned with their circumstances" after completing this activity.

Both exercises outlined above are meant to give parents a new perspective on their child, self, and life; to help them find benefits and positive meaning in ASD.

3) The third strategy/activity Dr. Grinman introduced for helping to facilitate PTG with parents of children with ASD involves journaling or what she calls "bullet journaling," which is an organization sheet that outlines what needs to be done and what short/long-term goals have been established. This activity helps integrate what is going on in the parent's heads and hearts and is meant to help them recognize their inner strength and offer solace in stressful times. When beginning this journaling process, parents are asked to write down three positive adjectives to describe themselves, three positive adjectives another person would use to describe them, and one thing they feel proud of about themselves. As the parents continue to journal, they are asked to write narratives assessing these internal and external strengths, which are discussed in depth with the clinician. The activities are intended to give parents a sense of empowerment, courage, self-confidence, and patience.

All three strategies help parents of children with ASD have increased self-reliance and recognition of their internal strength, given the challenges and judgments they will face in their parenthood journey.

For most of the 38 professionals in attendance in this training, this was the first time post-traumatic growth (PTG) was discussed for parents of children with autism. The attendees had prior knowledge of ASD and, some had worked directly with children diagnosed with this condition, but rarely had they focused on the parent's perspective and stress of dealing with this disorder. By the end of the training course, all trainees expressed interest in studying this field more closely and learning more about how these PTG factors can affect positive development and health in the family unit.

Personal Reflections

The Hudson Valley Professional Development training on post-traumatic growth in parents of children with Autism Spectrum Disorder provided attendees with a valuable overview of PTG and how it pertains to parents of children with such children. When I finish graduate school, I want to work with children diagnosed with ASD to determine how this neurological disorder

manifests and ways to mitigate the symptoms after onset. Since parents are the environment in which children grow and develop, it is equally important to understand their challenges and struggles when raising a child diagnosed with ASD. Parents' mentality and view of their child's diagnoses, and their role in supporting and nourishing that child's development, will be vital components in my research and practice. I took this training to gain a better understanding of PTG and to learn how, as a clinician, I will be able to both assess my patients (children diagnosed with ASD) as well as provide additional support for their parents to ensure the child has a secure family unit and dynamic. This training was very insightful and informative, providing very specific tools I can immediately use to nurture post-traumatic growth for parents. Attending this training gave me insights into the parent's perspective on how different and challenging it is to raise a child with ASD and introduced me to strategies I can incorporate into my practice that will benefit the entire family.

References

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EVENT OVERVIEW:

Title: Post-Traumatic Growth In Parents of Children with Autism Spectrum Disorders

Date/Time: Post-Traumatic Growth In Parents of Children with Autism Spectrum Disorders

Location: December 15th, 2022/12:00 PM EST

Moderator: Hudson Valley Professional Development

Panelist: Dr. Victoria Grinman



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Research

- https://adelphi.primo.exlibrisgroup.com/discovery/fulldisplay/cdi_proquestjournals_248065916/01ADELPHI%20INSTRUMENTALINSI
- <https://growingkindminds.com/media/>
- Grinman, Victoria. "A Retrospective Exploration of the Experience, Interpretation and Perception of Growth in Parents of Young Adults Diagnosed with Autism Spectrum Disorder." ProQuest Dissertations Publishing, 2020. Print.



Reported by Kirsten Richburg, a member of the Student Division of the International Association of Applied Psychology pursuing a masters' degree in the Department of Clinical Psychology, Columbia University Teachers College, and a student of Professor Judy Kuriansky's class on "Psychology and the United Nations." I am interested in working with children diagnosed with ASD to determine how this neurological disorder manifests and if there is a way to mitigate symptoms after onset and ensure the family dynamic is strong and healthy for the child's development.

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