



# A First-Stop Read for New Autism Caregivers and All Professionals: Review of Ala'i-Rosales and Heinkel-Wolfe's *Responsible and Responsive Parenting in Autism: Between Now and Dreams*

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Parents dream of the lives their children will lead—the people they will become, what the world will look like when they enter it as adults, and how they, as their parents, will fit into the story. Dreams take years to materialize and often don't match what parents first imagine. Between *now* and *dreams*, years and decades of parenting and life circumstances happen.

But what if the time between now and dreams is marked by the uncertainty of an autism diagnosis, the challenges of finding and paying for effective services, and redefining what it means to be a parent? Catherine Maurice grappled with these questions in her 1993 book, *Let Me Hear Your Voice: A Family's Triumph over Autism*. The story of her family's journey with autism was embraced around the world by parents in similar positions. It also influenced the visibility of and access to applied behavior analysis (ABA) services for autistic individuals (Detrich, 2018).

The autism services landscape of 1993 was fraught with challenges brought on by a lack of public knowledge about autism, limited service options, and prohibitive costs. Today's parents and caregivers also face difficulties, albeit more nuanced ones as innumerable ABA providers and funding options bid for their interest and attention (Trump & Ayres, 2020; Autism Speaks, 2019; Autism Speaks, n.d.). Private equity, rapid scaling-obsessed business models, and social media campaigns complicate a field saturated with choice and misinformation (NB Group, 2021). It overwhelms parents'/caregivers' ability to separate fluff from substance and to make decisions for their children. But 2023 is also a time of greater presence of autistic voices on social

media and in public forums (e.g., conferences, podcasts; #actuallyautistic movement, as described by Altay, 2021), and therefore opportunities for learning about their perspectives and for dialog about what matters to them.

The current terrain of ABA services can involve hurried transactions between clinician and family in which a caregiver's needs and concerns might not be addressed. New autism caregivers need hope and skills to carry them through many ups and downs. In *Responsible and Responsive Parenting in Autism: Between Now and Dreams*, scientist-practitioner Shahla Ala'i-Rosales and parent Peggy Heinkel-Wolfe provide important perspectives that are all the richer because of the authors' diverse experiences and perspectives (Ala'i-Rosales & Heinkel-Wolfe, 2021).

## Structure and Style

*Between Now and Dreams* is laid out in three sections: "The Power of Learning," "The Power of Connecting," and "The Power of Loving." Each part is filled with practical advice, stories of personal and professional experiences, and scientific findings that convey ideas and skills pertaining to these essential realms of living. The authors steer away from academic jargon and instead invoke a poetic but tough-love tone that encourages hope. For example, in the section on *contingencies*, they plainly describe appetitive and aversive stimuli and their influences on behavior: "Another fundamental of our learning is that there are things that we enjoy, that please us, that bring us safety, happiness, and pleasure. There are other things that we are repulsed by, that are aversive, and that bring us pain and harm. These wanted and unwanted events teach us how to approach, escape, or avoid" (p. 154). The authors also introduce concrete ABA concepts and current industry trends to help a caregiver engage in conversations with professionals, select ethical providers, and inform observations of their child's programming and progress (see

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chapters: “Science for Sale,” “Evidence-Based Treatment,” and “Being an Equal among Professionals”).

This book’s content allows readers to access it at any point during their autism journey, and sequential reading is not necessary to benefit from its lessons and ideas. Caregivers could be leaving an initial evaluation with a psychologist, sitting for months on a service waitlist while interfering behavior occurs at home, or seeing their child’s progress flat line. At each of these points, they can turn to the book for specific advice, skills, and emotional bolstering. The authors’ stories reach across ages, skill sets, and milestones, all of them infused with a hope-filled approach.

## Section Summaries

The book contains short, rich chapters grouped within its three main sections.

### The Power of Learning

Caregivers are the most important people in the life of an autistic child. While providers, services, and schools will change, caregivers are constant. That means caregivers will require new skills as that child ages and meets new professionals. Boundless sources of information and misinformation about autism and service options—including pseudoscientific, non-evidence-based treatments—will make it nearly impossible to find a singular source of truth (Foxy & Mulick, 2017). Ala’i-Rosales and Heinkel-Wolfe (2021) recognize that problem with a brief introduction to learning principles and a review of the history and evolution of ABA, as well as of autism services’ move into the profitable health care sector (see “Science for Sale”).

The authors don’t shy away from dark historical moments or current risks in ABA, but in their chapter “A Science of Love and Change,” they get to the hope applied behavior analysis provides: the creative use of shaping and reinforcement to produce meaningful behavior change. What stands out in these chapters is the sensitivity to neurodiversity and client-centered and assent-based care. They respond to a conundrum like *Should we try to change or limit access to this child’s specific interest because it doesn’t seem neurotypical?* with compassion informed by problem solving and family and cultural values.

In “Unexpected Places to Find Wisdom,” Ala’i-Rosales tells a story of repeatedly getting her dryer fixed by different repair people, always in the wrong way. Finally, one repair person finds the root cause of the problem. It isn’t the dryer at all, it was the hose and high temperatures. The story signals to caregivers that professionals may not put enough effort into identifying the real cause of a problem or they simply do not know how. You’ll get answers that don’t

seem right, but you have to keep pressing—your advocacy for your child is essential.

Two chapters identify attitudes that help or hinder caregivers and professionals during the autism journey. “Attitude Matters” has an example of flight school training, whereby pilots go through problem scenarios and learn how their decision making can be negatively influenced by impulsive, anti-authority, invulnerable, or resigned attitudes. “Shifting toward Halcyon Attitudes” discusses more productive ways of thinking and provides a guide to help caregivers reflect on their experiences. This reflection guide works through five goal outcome statements related to parenting (e.g., “I rise to face hard possibilities”) and follows with three to six reflection questions to aid the caregiver’s awareness of achieving the outcome (e.g., “Do I think the worst has already happened to my children and nothing worse can happen?”; pp. 116–117).

The final chapters of *The Power of Learning* honor children’s individual needs and discuss the importance of selecting the right therapeutic setting (home, center, or school) and interventions that allow high-impact learn-to-learn skills to mature through positive means. The authors introduce the concept of *behavioral cusps* and discuss how programming for cusps enables children to experience their worlds with greater meaning and nuance: “Sometimes learning a simple thing quickly opens new experiences and multiplies the possibilities, such as a young child learning to imitate or an adult with autism discovering the difference between seeing a basketball game on television and attending in person” (p. 128). The section ends with the authors’ return to their previous theme on assent-based care, this time adding Israel Goldiamond’s constructional approach as a way to improve outcomes and make for happier learning. Yummy Starts (Cihon, 2015), a constructional program that respects client assent and celebrates small-step progress to address food selectivity, is mentioned as a model that all services could resemble.

### The Power of Connecting

Caregivers learn best when they connect with other people: professionals, family, friends, community members, advocacy groups, and, of course, their child. In this section, stories about Heinkel-Wolfe’s son Sam, several of Ala’i-Rosales’s clients, and examples from published literature highlight the importance of developing reciprocal relationships. Though this takes time and careful planning to build, professionals and caregivers must be dogged about getting their children connected with their communities, which are filled with real-life opportunities to grow and access new reinforcers (Baer & Wolf, 1967; Kohler & Greenwood, 1986).

There is the story about 11-year-old Devon who uses his interests during a virtual basketball game to foster social

interactions with his cousins. He benefits from these relationships—learning to initiate social interactions and cooperatively play—and he gives a lot to the group as well: “The family often tapped Devon’s deep knowledge of baseball and basketball stats to enhance everyone’s enjoyment of the games” (p. 164). His cousins use Devon’s interests to build reciprocity and connection.

The same is true in Heinkel-Wolfe’s story about how, through carefully managed interactions over time, her son came to trust a hair stylist to cut his hair. Though haircuts began with hesitation, the authors note, “As he got older, Sam stopped telling Connie how to hold his hair and let her cut it as she would for any client. Then, the conversation became whatever Sam or Connie wanted to talk about. Getting haircuts became a powerful lesson in reciprocity” (pp. 166–167). This success engendered a certain degree of *willingness* that Sam would exhibit in future settings. Years later, when a dentist insisted on using sedation for all of Sam’s dental procedures, Heinkel-Wolfe and her husband challenged the recommendation—they knew their son had participated in dental and other procedures (haircuts) without any trouble, and that it was worth striving for the same here.

Heinkel-Wolfe’s story about the dentist segues into the second main theme of this section: both caregivers and professionals bring important information to the table, and collaboration between them leads to improved outcomes. “Sometimes we can explain and shift a professional’s perspective. Sometimes the professional shifts our perspective” (p. 181).

The chapters “Seeing around Our Blind Spots” and “Being an Equal among Professionals” are concerned with caregivers and professionals listening to one another, and partnering in ways that focus on a child’s self-determination and independence. Listening and partnering are valuable points for clinician-readers and ABA organizations asking what they can do to improve caregiver engagement in the therapeutic process. The authors note that finding shared purpose leads to improved engagement and collaboration: “Our shared purposes work like a giant orchestration: each person brings their training and talents to the team; together, the sound becomes something else altogether, something creative, new, moving, and powerful” (p. 186).

In “Sharing Wisdom and Responsibility,” Ala’i-Rosales and Heinkel-Wolfe write about caregivers who feel ineffective and intimidated in meetings with professionals. Quick transactions and professional lingo degrade their participation. To improve their engagement, the authors recommend a tactic derived from Heather Barahona’s research on how caregivers can advocate for their children in meetings with school professionals (Barahona, 2010). Barahona’s team gave parents a double-sided bookmark to carry to these meetings—one side with a picture of their child (the reason everyone was there), the other side with questions they could

ask. These bookmarks improved the parents’ advocacy and involvement. They also cued professionals to build inclusive environments for caregivers, just as they do for learners. Results of the small bookmark intervention were noticeable among teams: “The bookmark became an indicator of a shared reinforcer, reminding everyone on the team why the meeting was happening, while acknowledging and setting expectations for it. The bookmark cued respect for the team’s work in how they selected and measured goals for Barahona’s daughter and other children” (p. 210).

The section ends with advice on how to find collaborators and advocates for intentional connections in the caregiver’s community. “No parent raises a child alone because our community connects us. We weave a new fabric around our family as we join with people who share our concern for our child. Such intentional groups, called communities of practice, share a passion for progress and learning how to make progress” (p. 241). Ala’i-Rosales describes personal examples of connections with colleagues or families that turned out as long-term relationships where everybody benefited from the community. Caregivers may find their community of practice for whom they can lean on, and in return, who may do the same with them for years. They also include a valuable breathing and self-awareness exercise for caregivers to use in moments of stress to reconnect with other people in their lives. The exercise asks the caregiver to concentrate on their breathing, observe their feelings and reactions, and then consider the other person and observe their contributions to the situation. This step-by-step guide is a fairly reliable way to identify blind spots and collaboratively solve problems (pp. 244–245).

## The Power of Loving

*Love* is the power that aids caregivers in *learning* new things and *connecting* with new professionals and people throughout their parenting journey. But caregivers sometimes need to change their perspective on how to give and receive love. When a child does not connect with their caregivers in expected ways, caregivers can feel hopeless or distressed. They may need to redefine the reciprocal expression of love between them and their child—it is a critical step toward long-term engagement with the child as well as to their progress. In the chapter “Joy,” two parents video record happy interactions with their son Chavelo and then study the recordings to identify reinforcers, new behaviors to shape, and ideas to try. The videos also serve as markers of Chavelo’s progress, and their commitment to and love for him.

In “Walking through Love’s Dark Side,” Ala’i-Rosales and Heinkel-Wolfe acknowledge that fear, anger, shame, and grief can accompany a caregiver’s best efforts to love themselves, their child, and others. The authors describe how Israel Goldiamond’s (1974) contingency analysis of emotions can

raise flags for what is occurring in the contingencies operating in the family's life. This analysis provides professionals with insight they can use to collaborate and validate and respond to parental emotions. Through collaboration, they may begin to enhance desired contingencies and change unwanted ones.

Subsequent chapters examine shaping as a behavior change technique for teaching new skills and as a metaphor for approaching life. Shaping's emphasis on building small improvements that add up to discernible progress gives caregivers hope. Each small step is a victory that can lead to more loving environments in which to develop a child's skills and interests. This framework of optimism begs a comparison to forcing compliance and other approaches that too often lead to counter control by the child and disappointment for the caregivers.

For clinicians, this section emphasizes the importance of working with the family system. Ala'i-Rosales and Heinkel-Wolfe remind us that "Unless the decision-making includes our whole child, our whole family, and our whole cultural context, professionals risk doing their work in a self-serving, materialistic way" (p. 314). Good, sustainable work can be accomplished when families are included in the therapeutic process (Ala'i-Rosales et al., 2022; Lucyshyn et al., 2002; Slocum et al., 2014). The authors sum up the centrality of professional and caregiver collaboration when they write, "When well prepared, professionals will combine our family's wisdom with clinical evidence to make good recommendations for what is valuable and meaningful to our child" (p. 314).

"The Power of Loving" concludes with what could be deemed the mission statement for this inspirational book: "Humans need science and inspiration, it turns out" (p. 332).

### Guidance for Caregivers

*Responsible and Responsive Parenting in Autism: Between Now and Dreams* was written with caregivers top of mind. Peggy Heinkel-Wolfe's influence is most noticeable when stories about her autistic son, Sam, carry the narrative. Her experience as a journalist and award-winning author also shape other sections and the book's overall accessibility. Some chapters are high level with big ideas (see "Sharing Wisdom and Responsibility"), while others are decisively practical with action steps (see "Shifting toward Halcyon Attitudes").

Ala'i-Rosales and Heinkel-Wolfe judiciously present behavioral concepts for caregiver-readers through examples and application relevance. One such example is their description of *shaping*, which mentions the systematic use of reinforcement, increased response requirements, and contingency creation and management. To enhance accessibility of the topic, the authors introduce shaping as a two-page

sidebar separated from the chapter's main narrative (pp. 296–297). This format helps readers learn the concept, identify it in other parts of the book, and reference it easily later on. In other cases, the authors use stories and metaphors to describe behavioral concepts so that caregivers can more readily grasp an idea. The chapter "Evidence-Based Treatments" demonstrates this approach when the authors reference Glenn Latham's way of discussing how data patterns inform the tailoring of a clinical program: "In *An Angel Out of Tune*, [Latham] likened our parenting journey to a cross-country road trip listening to AM radio. As we pass through regions, we lose the frequency of the local stations. We keep our eyes on the road as we drive, but continually and responsively adjust the dial to stay in tune. Likewise, a skilled therapist continually adjusts to find the evidence and respond to our child lovingly and with flexibility" (p. 85). Although intended for caregivers, the book is not the next parenting guide on ABA concepts. Rather, it's meant to inspire caregivers who, at times, find parenting stressful and lonely (Davis & Carter, 2008; Padden & James, 2017).

Although focused on caregivers, lessons from the book are applicable to professionals, new and experienced. Professionals might also hand a copy of the book to new autism caregivers as they begin their journey to parent and experience ABA services.

### Guidance for Professionals

*Responsible and Responsive Parenting in Autism: Between Now and Dreams* sheds light on caregiver experiences and treatment evidence that can inform a professional's practice and relationship with families. Most of this information—for example, topics on client-centered or assent-based care—is presented in layperson language and stories. Although it makes for an enjoyable read, these sections are, in fact, replete with technical nuance. In the section on behavioral cusps, for example, a clinician-reader would want to consider whether what they do in clinical programming meets the key points the authors outline. This information could be easy to gloss over amid the narrative writing. Further, Ala'i-Rosales and Heinkel-Wolfe are adamant about the role of context and culture in service delivery—every topic in the book (assessment, programming, setting, etc.) should be judged against the culture and context of the family. Clinician-readers familiar with the growing literature on compassionate care and therapeutic relationship-building (Taylor et al., 2019) will be pleased to find these principles and skills laid out in positive examples.

A professional/clinician-reader should carefully consider the concepts and ideas in this book and seek out mentorship to apply them in their clinical practice. Learning and applying the ideas requires introspection—a core theme of *Between Now and Dreams*.



## Conclusion

Many books describe how caregivers and professionals can implement ABA effectively with an autistic individual. Far fewer texts combine scientist-practitioner and caregiver perspectives with real-world sensibilities and inspiration. In their resolve to find answers and relief quickly, caregivers can expend their energy, attention, and resources in dozens of unsatisfying directions. Ala'i-Rosales and Heinkel-Wolfe make a compelling case for staying focused on finding ethical providers, creating happy learners, collaborating with professionals, and seeking support systems. The ABA community needs books like this one to help us get from where we are now to our dreams.

The authors have created a supplemental study guide for professionals. With this tool, it's possible to organize a book club, read and discuss with colleagues, and promote the application of the concepts in your organization to improve outcomes for clients and their families. The study guide is available on the publisher's website: <https://tinyurl.com/p9nbvf7h>.

## Rating

5 out of 5 stars for structure, content, and practical advice that will serve caregivers and professionals throughout their autism journey.

**Data Availability** Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

## Declarations

**Ethical Approval** Research was not conducted for this review article and is not subject to ethics committee oversight.

**Conflicts of Interest** The author declares no competing financial or non-financial interests related to the content of this article.

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