

Child on the Rainbow: Parents talk about what it is like to receive a diagnosis of disability of their babies and toddlers

By Dalia Shlomy, Maree Foley, Dror Yifa, Mira Fahima, Smadar Safrai, Anat Bruner and Liora Bloch

This paper is aimed to support practitioners and clinicians to further understand the parents' experiences of receiving a diagnosis of disability concerning their child. Drawing on the work of Dalia Shlomy and the parents engaged with "Child on the Rainbow" (2014), this paper offers a window into the lives of the babies and young children, with their parents, and in relationship with their community.

In summarizing, how the *Child on the Rainbow* (2014) project came about, Dalia Shlomy reflected:

The play, "Child on the Rainbow", was created through a relationship between a parent group counsellor and a music teacher, who was also a parent of a child with special needs. From this beginning, of two people, the idea was welcomed by a group of parents to children with special needs. These parents were members of the "Alei Cotert" club operating in the Izrael Valley regional council in Israel.

The raw material for the play evolved from one and half years of playback theatre recordings within which the group explored personal difficulties associated with raising a child with special needs, and with the support of the group, the ensuing journey towards peace and acceptance; of the diagnosis, of their child and of their relationship with their child. Next (which took a further one and half years) a professional director transformed the raw material into a 9-scene play.

Each scene tells a parents' story of their experiences of, for example, coming to terms with

the diagnosis, shame, family relationships, society's attitudes, and prejudices. The play also contains poetry, including one piece written by Chanoch Levin (A known Israeli play writer). You can watch the play from the following link: <https://www.youtube.com/watch?v=IjjBelYpt4&t=17s>

In preparation for this paper, Maree asked Dalia, if it would be possible to hear more from the parents who feature in the *Child on the Rainbow*, about their early days with their infants and toddlers; who are now grown up. Upon this request via Dalia, the parent's generous responses, shape the heart of this paper. Within the translation from Hebrew to English, as much as possible, we have not changed or overly edited the parent's stories. In doing so, our intention has been to bring into view the voice of the parent, as if we were sitting together, listening to these remarkable people, remarkable parents. We begin with Mira and Barak's story.

Mira and Barak's story

Barak was our fourth child. After two girls and one boy I thought I know everything about children and parenthood, but then Barak was born and changed all my ideas. He was a very happy child, did not cry at all but he was very active. Then I noticed that he is not doing what he should do, the first thing was to follow after a moving object. He was looking straight without following with his eyes.

The Doctor sent us to a special test, and they told me that biologically everything is all right. Maybe it's a matter of slow development.

As the years passed, we noticed that everything was a slow process. He was late standing, late walking, and slow speaking.

It took him some years to start speaking. At the age of 3 he still did not speak. Everyone around us comforted us that times will come that we'd like him to stop talking.

Today he is speaking fluently, but still got problems of pronounce everything right.

The super hyper - activity was shown at the age of 4, when he went to the kindergarten. All the children could sit very quietly listening to their kindergarten teacher, but Barak could not sit. After few minutes he felt that he must walk or run. This, of course was a kind of an interruption at the kindergarten. They wanted to give him the medicine RITALIN, but we objected to give him this medicine because it is a psychiatric type.

I still remember that during all his childhood I was in some kind of struggle, all the time, against the education team. I felt that I am his voice and representing his rights.

The main thing I was doing in that period is running after every idea or every new method that can help him or cure him. I was absolutely sure that along the time he will be okay and that he will be involved in the lives of his peers.

That never happened.

Till now he is suffering from lack of friends and he is a very lonely guy.

My name is Mira and my son BARAK is 34 years old.

As we think about Barak, now 34 years old and his mother Mira, their story illustrates the connections between child, family, and community. Further highlighting this point, Falik (1995) reminds us that an infant and or young child's diagnosis is at least a triadic experience including the child, their family, and the community.

Furthermore, in response to a diagnosis, the literature uses terms such as resolution and *non-resolution* (Marvin & Pianta, 1996). Based on phenomenological studies of parents, Heiman (2002) found *resilience, coping and future expectations* as core features to appreciate in the process. Barnett et al. (2003), consider the process of *adaptation* to better encapsulate the parents' experiences over time:

We define adaptation as an ongoing process whereby parents are able to sensitively read and respond to their child's signals in a manner conducive to healthy development... we contend that parental perceptions, thoughts, and emotional reactions to their child's condition are effective avenues for promoting adaptation. (Barnett et al., 2003, p. 184)

In day-to-day terms Barnett et al (2003) state that "healthy adaptation" (p. 197) is central to the development of the quality of the attachment relationship.

Ideally, parents increasingly are able to learn to love, appreciate ... their child. As the child develops a secure attachment, the parent and child are able to build new Dreams together. (Barnett et al., 2003, p. 197)

In addition, much has been researched regarding the correlation between a parents reactions and capacities in response to the diagnosis, their caregiving, and their unique infant-parent attachment relationships (Oppenheim et al., 2007; Sher-Censor, Doley, Said, Baransi & Amara, 2017; Sher-Censor, Ram-On, Rudstein-Sabbag, Watemberg, & Oppenheim, 2020).

Furthermore, as the parents voices below indicate, diagnosis can enter the lives of a family at different ages and developmental stages. Indications that prompt a health inquiry in infants and toddlers is required, is not always evident at birth. Within this amazing group of parents, some did not enter the world of diagnosis until their children were older. Continuing the

conversation begun by Mira and Barak's story, we now have the opportunity, to listen to the stories of: Smadar and Lishay; Dror and their son; Anat and her daughter; and Liora and Ofri.

Smadar and Lishay: Their story

This is the story of Lishay our first-born child.

We were a happy young couple with a normal pregnancy excited to become a family.

Lishay was born on the 38th week of the pregnancy in a cesarean section due to complications that left him barely alive.

The doctors managed to save his life, but they informed us that Lishay had suffered severe damage in large areas of his brain.

It was so severe that they couldn't tell us if he would be able to walk talk or see...

With this uncertainty we began our journey.

From the very beginning, Lishay proved to be a strong and optimistic character.

Three times a week he was practicing physical therapy as well as speech therapy and although it was pretty intensive, he always smiled and did it over and over again.

At the age of two and four months after endless falls and injuries, Lishay began to walk!!!

There are no words to describe how happy and proud he was... (as us)

We learned that Lishay has no limitations and he kept surprising us with his achievements.

Lishay walks, talk's, sees with a very strong life, loving personality, keeps smiling to the world, even if the world doesn't always smile back to him.

Having a child like Lishay and

the journey we share together, has made me a better stronger person, not afraid to face any challenges life may bring my way.

Lishay opened my eyes and soul and there is not a day gone by without me being enriched by him.

The meaning of the full name Lishay Tuvia that we chose for him before he was born, in Hebrew is: my God grace gift, which amazingly was profiled!

SMADAR PROUD MOM

Dror and their son

Our son was diagnosed when he was around 11 years old on the autistic spectrum. Till then he was functioning almost as his friends. Although he seldom invited friends or was invited by them, we never thought that he straggles Asperger Syndrome. We noticed it only some years later, so we didn't deal the subject the first years.

Anat and her daughter

In the first few months, I did not notice any particular difficulty. A beautiful baby, sleeps well, eats well. She didn't smile or laugh, but I didn't understand what that meant. Towards the age of one year, I began to be disturbed. She didn't murmur at all. When I showed her pictures in the book, she couldn't point to things I showed her.

After age one year she could not follow a simple instruction. I was more troubled but didn't think in terms of a "problem". As she is the fourth child in the family and as the signs of something going wrong increased, the worry grew. We checked hearing, vision, everything is fine. My concern grew more and more disturbing and frightening: what was happening to her? What is the problem? What will it be?

At the age of two and three quarters, we reached a developmental physician. She spoke about Slow Development. Since it was not a Developmental disability, I felt rather encouraged that the gap would be closed later. In spite of treatments at the speech therapist and occupational therapist, this did not happen. The gap between her and same age children, especially in understanding the language and social codes, grew wider. The anxiety of not knowing what the definition of her problem is, was actually increased.

At age 5, we were still in that situation. We were looking for all kinds of therapists and ways to help and promote her. Every afternoon, I, her mother, was busy playing with her and teaching her how to play.

Liora and Ofri

It started with a fever seizure. Ofri (second child in the family) was one year and five months old. There was something in the air before. There was a feeling that something in the development, wasn't quite right - but the problem was hard to pinpoint.

Losing his consciousness during the seizure was, for me, an experience of a mother who lost her child. I thought he was gone. It was a silent shock to me. I vividly remember my wonder when I heard him cry and realized he was alive. My mother told me at the end of that day that I had aged ten years in a day. I was 33 at the time.

An entanglement of hospitalizations, tests and diagnoses began. The seizures were repeated and in fact, Epilepsy and Slow Development were diagnosed. I remember very well, how heroic, brave, I was at the time of hospitalization - and

on the contrary, the fall of spirit when we returned home. But the fall was short. No more than a few hours. We were surrounded by an extremely supportive extended family and friends who were equally helpful.

Ofri began medication treatment that disrupted all his systems. He was confused, hyper-active. We had to keep an eye on him at all times. There was a therapeutic set of routines we needed to keep. And in spite of all this, at home the joy of living never ceased. We dealt with the situation with a lot of humour and most of all in his acceptance and exposure outside in the most transparent way.

Time went by. At the age of six, a Comprehensive Diagnostics was performed, at the end of which came the bad news - Ofri suffers from light Mental Retardation.

This letter was a slap in the face. It was the first time it was written in black and white.

One had to deal with the absolute knowledge that it was not something that will go away, the various treatments might improve his function - but in fact it was our child who would never be "normal".

I remember when Ofri was about three years old, we went to a family holiday dinner at my parents' home. How much I cried on the way. This thought that everyone comes with their healthy children - and we are taking care of a sick child with a mountain of related problems.

Looking back - it was hard, but we made a wonderful journey.

And the proof is - this is a 30-year-old, communicative and happy guy, high-functioning, independent, earning a living, his world is full of good and mostly - and most importantly - happy.

While we pause to take in the power, pain, and hope, of these lived stories, it is difficult to know exactly how to move from here, back into theory. But in fact, that is one of the steps of the dance we do together as parents and children with professionals, and as professionals, with parents and their children.

One way that does seem to bridge these different lenses on understanding, is the Reaction to Diagnosis Interview (RDI) (Marvin & Pianta, 1996). The RDI offers a meaningful and structured way to learn and discover together about the journey so far. Of note, the RDI has been adapted to a shorter self-report form of the "Reaction to Diagnosis Questionnaire" (RDQ) (Sher-censor et al., 2020).

A useful, brief summary of the RDI is provided below. It was used as part of a training promotion, presented by Marvin (2013) in Italy:

The Reaction to Diagnosis Interview (RDI) (Pianta & Marvin, 1992) is a brief, 15-minute interview, derived in part from Mary Main's concept of "resolution of trauma or loss" originally developed as part of the Adult Attachment Interview (George, Kaplan & Main, 1985). The RDI examines resolution of the potential loss/trauma associated with the experience of learning that one's child has a disability or chronic illness. Parents report this to be a period of crisis: the family's routines are disrupted, expectations for the child may be challenged, the parent may feel guilty or may search for a very personal reason/cause, and their sense of themselves as effective parents is challenged. Parents vary in their reports of the diagnostic experience and its aftermath, in their ability to reflect on these experiences, and in their ability to turn their attention to the present and future regarding their child. In other words, parents vary in the degree to which they are able to resolve the crisis of the diagnosis. The RDI assesses this resolution or lack of resolution through videotaping and then coding an individual parent's

responses to 6 standardized questions with specific probes. The interview requires 10-20 minutes to administer, and 30-40 minutes for an experienced and certified professional to code. The coding yields major classifications of Resolved and Unresolved, plus a number of sub-classifications within each major classification. These sub-classifications are helpful in the coding process, and are useful for planning and conducting interventions (<http://www-5.unipv.it/users/aip2014/images/1.RDIWorkshopFlyer-Pavia2013.pdf>)

To further elaborate, interview questions within the RDI (Marvin & Pianta, 1996) include:

1. *When did you first realize that your child had a medical problem (probe for details)?*
2. *What were your feelings at the time of this realization?*

3. *How have these feelings changed over time?*
4. *Tell me exactly what happened when you learned of your child's diagnosis. Where were you, who else was there, what were you thinking and feeling at that moment?*
5. *Parents sometimes wonder or have ideas about why they have a child with special needs. Do you have anything like that that you wonder about?*

Analysing the Reaction to Diagnosis Interview results (as shown in Table 1) we can understand the parent's place in relation to the diagnosis and adapt our professional counselling to the parent situation. Parents who have come to terms with the diagnosis will demonstrate emotional change, acceptance, hope, and will deal with the cause of the difficulty. Parents who have not yet come to terms with the diagnosis may exhibit one of the following signs: emotional detachment, emotional flooding, anger, depression, disorganization, cognitive distortion, and confusion.

Table 1. Signs of Resolution and Lack of Resolution from Pianta & Marvin (1996) and its Reflection in "Child on the Rainbow" parents monologs (Shlomy, 2014).

Evidence of resolution	Signs of lack of resolution
Acknowledgment of emotional difficulty of learning of the diagnosis	Denial of emotional impact of diagnosis
Recognition of change reaction since learning of the diagnosis	Cognitive distortion related to child's diagnosis or abilities
Suspension of search for an existential reason for child condition	Confusion and mental disorganization (contradicting oneself, loss of memory)
Acknowledgment of the need to move on in their life	Active search for existential reason for child's condition
Accurate representation of child ability	Disoriented or stuck in the past
	Boundary violations (attempts to draw interviewer into collusion against medical personal)

Conclusion-Pause

Carpenter (2005) states:

At the point of diagnosis of a child's disability, a parent's first question is hardly likely to be about the local early childhood intervention services. These families are frightened, disturbed, upset, grieving and constantly vulnerable. The role of the professionals involved with them is to catch them when they fall, listen to their sorrow, dry their tears of pain and anguish, and, when the time is right, plan the pathway forward. (p. 181)

As we find a place to conclude, it seems more apt to consider this as a place to pause because the conversations, the experiences for the parents and their now adult children, is ongoing, daily. Throughout the *Child in the Rainbow* project, Dalia Shlomy has managed to artfully bridge theory with practice while keeping the heart of our work, babies with their parents in their communities, at centre stage. The play, *Child on the Rainbow* has been performed more than 20 times during the past five years in front of parents and professionals together. And furthermore, after the final applause, what happens next at each show: an open discussion between Dalia Shlomy as the producer, the parents who are the actors in the show, and the audience. So, it seems apt to pause here, before we invite your enquiry and conversation, with a word of thanks to each parent and their child:

Mira and Barak, Thank you.

Smadar and Lishay, Thank you.

Dror and their son, Thank you.

Anat and her daughter, Thank you.

Liora and Ofri, Thank you.

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Poems and Reflections

By Deborah J Weatherston, PhD, United States of America

Deborah Weatherston, PhD (Infant Mental Health Specialist and Mentor) is the recently retired, Executive Director, Alliance for the Advancement of Infant Mental Health. She is also a long-standing Editor-in-Chief, and more recently Associate Editor, of *Perspectives in Infant Mental Health*.

Debbie has been reflecting via poetry, on her experiences as an infant mental health home visitor, and in parallel, experiences within reflective supervision. A selection of her poems, with a reflective commentary from Debbie, about how her poems arrived, have been published in the Poetry and Practice section of Newborn Behavior International (NBI) network website.

You can access her poems and reflections via the following link: <https://www.newbornbehaviorinternational.org/poetry/name-of-poem-bxjh5>.



More generally, about the site, this is open access site and contains an invitation from NBI leaders, Kevin Nugent, and Lise Johnson, to join the NBI worldwide network.

You can read more about this at the following link: www.newbornbehaviorinternational.org

How can online learning improve child mental health – on a global scale? -Online presentation from Dr Niels Peter Rygaard (Denmark)



How can online learning improve child mental health – on a global scale? Who needs us the most? Children who lost parental care! Here is a link to this online presentation at the APA Convention by Dr Niels Peter Rygaard (Denmark), who was awarded the APA International Humanitarian Award. He has generously shared this link with us all. Thank you Dr Rygaard.

The link: <https://www.youtube.com/watch?v=Epmju564FTU>.

Book announcement

Recently published infant-parent psychotherapy book for sleep problems

Recently released book by Dilys Daws with Sarah Sutton (2020). Parent-Infant Psychotherapy for Sleep Problems. Through the night.

<https://www.routledge.com/Parent-Infant-Psychotherapy-for-Sleep-Problems-Through-the-Night/Daws-Sutton/p/book/9780367187828>