



Comprehensive Training Programme for Informal Advisors for
Parents of Children with Disabilities

MODULE 4

**MANAGING FAMILY LIFE WITH DISABILITY:
EMOTIONS, ROLES AND INCLUSIVE SUPPORT**

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**INNOVATIVE SUPPORT AND EDUCATION FOR PARENTS OF CHILDREN WITH
DISABILITIES THROUGH INFORMAL ADVISING**

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Contents

4. Managing Family Life with Disability: Emotions, Roles and Inclusive Support	3
4.1. The Emotional Process Experienced by Families	3
Introduction	3
Understanding the Emotional Spectrum (Shock, Denial, Anger, Grief, Acceptance)	4
Shock and Denial	5
Guilt and Anger	7
Grief and Bargaining	9
Acceptance and Reorganisation	11
4.2. Parental Roles and Their Effects	13
The Effects of Role Changes	16
4.3. Balancing Family Roles and Including Siblings	20
Strategies for Balancing Roles	21
Involving Siblings in the Process	23
4.4. Ethical Principles in Informal Counseling	27
Creating a Support Ecosystem	27
Counseling and Information Sharing	32
Questions and Answers	35
Bibliography	37

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4. Managing Family Life with Disability: Emotions, Roles and Inclusive Support

4.1. The Emotional Process Experienced by Families

Introduction

This section has been prepared to normalise the complex emotional process that parents experience after a diagnosis. It is crucial to view these as common reactions rather than a linear, inevitable path.

The emergence of disability within a family unit functions not merely as an isolated medical event but as a systemic catalyst that fundamentally alters the psychosocial equilibrium of the household. From a family systems perspective, the diagnosis or onset of a disability triggers a ‘crisis of change,’ a critical turning point that requires a profound restructuring of established roles, future expectations, and daily functioning. While the physiological reality of disability resides in the individual, its psychological impact spreads throughout the entire family network, initiating a complex, non-linear process of emotional adjustment.

The initial phase is often characterised by shock; this is a physiological and psychological numbing that acts as a protective mechanism against the sudden trauma caused by the diagnosis. This cognitive dissonance usually leads to denial, i.e. consciously or unconsciously refusing to accept the permanence or seriousness of the situation. In this context, denial should be seen not only as a deficiency but as a temporary buffer that allows the family system to mobilise the psychological resources necessary for long-term coping.

As the reality of the caregiving environment solidifies, anger frequently emerges. This emotional fluctuation may be projected onto medical professionals and spiritual entities or turned inward as guilt and self-blame. This stage is inextricably linked to mourning the ‘idealised child’ or the loss of the expected family narrative. This ‘chronic grief’ confirms the disparity between the expected life trajectory and the reality that has emerged.

Ultimately, effective family resilience depends on movement towards acceptance and adaptation. Acceptance does not imply the absence of pain or hardship; rather, it refers to a cognitive reframing in which disability is integrated without dominating the family's identity.

This signifies a shift from a passive state of endurance to an active state of management characterised by the restructuring of roles and the active demand for inclusive support systems.

To further clarify the emotional landscape discussed above, the following definitions frame the psychological progression within the section: Shock Mechanism: Defined as a state of imbalance in which cognitive processing is temporarily suspended. In the context of a disability diagnosis, this often manifests as an inability to retain medical information or perform routine tasks due to the sudden disruption of the 'assumed world'. Defensive Denial: Examined as a regulatory strategy. While prolonged denial may hinder early intervention, belittling at certain periods may prevent psychological collapse and allow the family to assimilate the diagnosis in manageable stages. Displaced Anger and Guilt: Understanding anger as a secondary emotion stemming from fear and powerlessness. This includes 'existential anger' (questioning the justice of the universe) and disappointment regarding lack of social accessibility. Grief Cycle (Chronic Sadness): Unlike the grieving process where the object of loss is gone, families with disabilities experience 'ambiguous loss.' The individual is present, but the expected personality or future is lost; this leads to a recurring grieving process triggered by developmental milestones (e.g., a child not walking at the typical age). Restorative Acceptance: Reorganisation of the family system. This involves redefining the concept of 'normality', advocating, and shifting the focus from the limitations of disability to the individual's abilities and the resilience of the family unit.

Understanding the Emotional Spectrum (Shock, Denial, Anger, Grief, Acceptance)

The emotional reactions to a child's diagnosis are often compared to the stages of grief famously conceptualised by Elisabeth Kübler-Ross (1969). It is crucial to emphasise to parents that this is not a linear process. They may skip stages, revisit them, or experience several simultaneously.

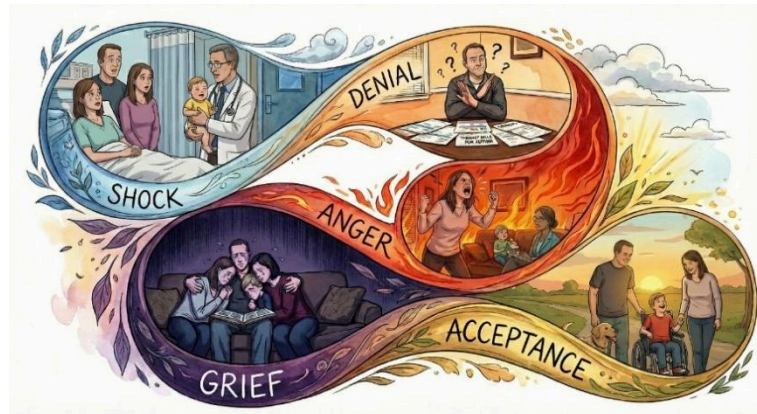


Figure 1. The Emotional Process Experienced by Families with Children with Special Needs

Shock and Denial

The shock phase is the initial reaction parents have when they receive a diagnosis or realise that something is different. It is a state of physical and emotional ‘freezing’. During this period, the brain is so overwhelmed by the news that it temporarily shuts down to protect itself. Parents often describe this moment as feeling like being struck by a heavy object or as if time has suddenly stopped.

The following conditions may be observed in parents during this stage:

Numbness: At first, you may feel nothing. You are physically present, but your mind is far away.

Physical reactions: Feeling cold, trembling, uncontrollable crying, or feeling unable to breathe.

Tunnel vision: You may see the doctor's lips moving, but you cannot hear what they are saying.

Case study: Sinem takes her 2-year-old son to a specialist. The doctor explains that her son has autism. Sinem nods politely, goes to her car, and sits staring at the steering wheel for an hour. She cannot remember a single word the doctor said after the word ‘autism’. She is not sad yet; she is just frozen.

After the initial shock passes, disbelief sets in. This is the brain's way of saying, ‘I can't handle this yet, so I'll pretend it's not happening.’ This does not mean that parents do not care; it is a defence mechanism to keep hope alive and delay the pain. At this stage, parents may experience the following:

Denying the diagnosis: Thinking that the doctors made a mistake or that the test results were mixed up.

Downplaying the problem: Convincing yourself that the problem is temporary or minor.

Doctor shopping: Going to many different doctors, not to get help, but hoping to find someone who will say that nothing is wrong.

Case study: *Mahir's daughter was diagnosed with a hearing impairment. Mahir insists, 'She hears fine; she's just stubborn like her mother.' He refuses to sign the paperwork for a hearing aid and insists 'it will go away' by next year. He spends weeks researching stories of medical errors online to prove the doctors are wrong.*

It is important to remember that shock and disbelief are normal. They serve as an emotional 'painkiller.' They allow the family to digest the news in small, manageable chunks, so that the full reality does not overwhelm them all at once.

Denial, however, is an escape from reality. In the denial stage, parents are not ready to accept the lifelong nature of the disability. Instead of facing the harsh reality, the mind tries to find an easier explanation. It acts as a shield protecting the heart from pain until it is strong enough to bear the truth.

Denial does not usually appear as a complete rejection of the doctor's words. Instead, it often appears as finding excuses or downplaying the problem.

The most common ways denial manifests in family life:

The 'Late Bloomer' Explanation: Parents often convince themselves that their child is not different, just slower than others. They seek out stories of people who struggled early on but later turned out 'fine.' "My uncle didn't speak until he was four, and now he's an engineer. My child will improve over time." Therefore, believing that the child will naturally improve on their own, they delay speech therapy or early intervention.

Blaming the Environment: Instead of accepting that the child has an internal problem (such as a learning disability or sensory processing disorder), parents may blame external factors. Thoughts such as 'He behaves this way not because he has ADHD, but because his teacher is too strict' or 'He's not ignoring us; the house is too noisy' lead to behaviours such as constantly changing schools or parenting styles, in the hope that the problem will be solved by the 'perfect environment'.

Functional Denial ('Super Parent'): Sometimes denial appears as working excessively hard. Parents may believe that if they try hard enough, exercise enough, or take enough vitamins, they can 'cure' the disability. The prevailing thought is, 'If we do this therapy 40 hours a week, next year she won't be autistic anymore.' Because of this, they may push the child (and themselves) to the point of exhaustion to 'beat' the diagnosis..

Case study: 'Just Shy' Narrative

Aleyna's daughter Safiye has been diagnosed with severe social anxiety and developmental delay. However, when her family comes to visit, Aleyna acts as if nothing is wrong. When Safiye hides under the table and refuses to make eye contact, Aleyna smiles and tells the guests, 'She behaves like this to get attention when you're around because she didn't take her afternoon nap.' Aleyna knows the diagnosis, but she rewrites the story in front of others, and often to herself, to make it seem 'normal.' Accepting the truth feels like accepting defeat.

Denial usually disappears when the difference between the child and their peers becomes too great to ignore. For example, when other children start reading or riding bikes and their own child does not, the excuses no longer work. This is painful, but it is necessary in order to move on to the next steps.

Guilt and Anger

Anger, which usually arises mixed with feelings of guilt, can be directed at medical professionals, one's spouse, oneself, God, and even the child.

Guilt often manifests itself in thoughts such as 'Could I have done better?' or 'Is this my fault?' The most common manifestations of guilt are listed below.

Guilt about the child's condition: Seeing oneself as the cause of the child's needs, thinking that actions (or inactions) during pregnancy or birth affected the situation. Constantly re-examining medical reports or past events, thinking 'If only we had noticed earlier'.

Feelings of inadequacy and guilt about care: Believing that one has not cared for the child well enough or has not fully met their special needs. Criticising oneself harshly when the child's therapy or education is disrupted, constantly feeling pressure to be the perfect parent.

Guilt towards other children (healthy siblings): Thinking that caring for the child with special needs reduces the time, attention and resources (financial/emotional) available for other

children. Feeling sad about not being able to spend special time with the healthy sibling, feeling guilty that the sibling cannot have a 'normal' childhood.

Guilt about meeting one's own needs: Thinking that taking time for oneself means stealing from the needs of the child with special needs. Feeling selfish even when wanting to take a short holiday, take up a hobby, or simply relax.

Anger is usually an expression of feelings of disappointment, helplessness, and injustice. The most common manifestations of anger are listed below.

Anger towards diagnosis and the system: Late diagnosis of the child, lack of appropriate treatment or educational services, bureaucratic obstacles. Developing harsh criticism and distrust towards doctors, therapists, schools or government agencies.

Anger towards spouses (partners): Believing that the burden of care is not fairly distributed, perceiving that the spouse does not sufficiently understand or support the situation. Frequent and intense arguments, even over minor issues, silent tension (sulking) within the home.

Anger towards the child: The child's behavioural problems (tantrums, sleep problems, lack of communication) or the parent's exhaustion due to the constant burden of care. Showing a harsh reaction towards the child in a moment of sudden raised voice or complete loss of patience (this usually creates a strong feeling of guilt immediately afterwards).

Anger directed at the social environment: Judgmental looks, inappropriate comments, or lack of sufficient support from the environment (relatives, friends, society). Withdrawal from relatives, defensive or aggressive reactions to judgemental looks encountered outside, rebelling against fate with the question 'Why us?'

Case study: The Silence of Guilt

Elif was preparing her 7-year-old son Ege, who has autism spectrum disorder, for bed. In the dim light of the room, she stroked Ege's cheek. Ege was sleeping peacefully after a day of therapy and the noise at nursery. Elif sat on the edge of the bed and sighed heavily, the weight on her shoulders, the same thoughts circling in her head: "I shouldn't have gone on that business trip before the birth. Stress... it was all because of stress. Or that medicine the doctor

mentioned... I wish I had taken that medicine. I didn't fully understand his first years. I missed all the signs. I'm not a good mother."

These feelings are normal and part of the family's grieving process. The important thing is to learn to express these feelings in healthy ways and develop coping mechanisms.

Grief and Bargaining

This is a critical stage. Parents mourn the loss of the “expected” child and the future they had imagined. As defined by Olshansky (1962), this is a chronic grief that can resurface at significant milestones (e.g., the first day of school, birthdays).

Grief (sadness) is a deep sorrow over the loss of the ‘ideal’ child the family expected and imagined and the ‘normal’ family life. The most common manifestations of grief and mourning are listed below.

Mourning for the expected future (chronic grief): This is a recurring sadness at each developmental milestone in the child's life (starting to walk, going to school, socialising, etc.), rather than a one-off event. This grief is triggered again when the family realises that their child is lagging behind their peers or will never be able to do certain things. Avoiding seeing the achievements of peer children at family gatherings or on social media, withdrawing when such topics are brought up, or experiencing sudden emotional outbursts.

Sadness caused by social isolation: Due to the burden of caring for a child with special needs and the fear of social stigma, the family gradually withdraws from their social circle. Activities that were once easy (going to a restaurant, going on holiday) become difficult, creating deep loneliness and sadness in the family. Constantly declining invitations from friends and relatives, withdrawing into the home with a feeling of ‘not being understood’ and a decline in communication within the marriage.

Loss of energy and motivation: Constant care, financial difficulties, and chronic stress cause burnout in parents. This manifests as a state of constant fatigue and discontent. Difficulty maintaining daily routines, giving up hobbies, difficulty showing interest in each other, and indifference to household chores.

Case study: The Cold Walls of Grief

It had been three months since the diagnosis, but Lale's life had frozen that day. Their home, once cheerful and lively, had now fallen silent under the weight of the reality that İpek would never learn to speak. Lale was overcome with sobs as she watched videos of İpek's meaningless baby sounds. "Those sounds... They're gone now. Will I never have a normal mother-daughter conversation with my daughter? Will I never hear her say "Mummy"? The child of my dreams is gone now. All that remains is this deep silence." Lale shut herself in her room. She didn't answer her friends' calls and refused to go out. This grief had completely cut her off from her social circle.

Bargaining is an attempt to regain control in order to change the situation, usually a mixture of hope and helplessness that emerges in a kind of “if... then” formula. The most common manifestations of bargaining are listed below.

‘I can do more’ bargaining (intensive therapy search): The family makes excessive efforts to completely resolve the situation or at least significantly improve it. This involves seeking out numerous and intensive different therapies or alternative treatments, often to the point of pushing the child's limits.

Reflection in family life: Devoting all or a large portion of financial resources to experimental/expense treatments, one parent (usually the mother) taking on the role of full-time therapist, constantly researching new doctors and methods.

Bargaining with faith/fate: The family may believe that they must make a promise to something (God, the Universe, etc.) or sacrifice themselves in exchange for changing the situation. Thoughts such as, ‘If I become a better person, do more good deeds, my child's condition will improve,’ lead to a tendency towards excessive self-sacrifice and neglect.

Bargaining to avoid guilt: The family tries to prove they can control the situation by constantly attributing the cause of the illness/situation to external factors or people around them. This is also a way to escape their own feelings of guilt. Attempts to show that they are trying to remedy the situation by criticising their spouse, doctors or those around them. (‘If my spouse had been more careful...’ or ‘If this doctor had made the right diagnosis...’).

It is important to remember that these stages are cyclical and that families may constantly go back and forth between grief, anger, bargaining and acceptance.

Acceptance and Reorganisation

This stage is not a 'happy ending' or a state of "escape" from grief. Acceptance involves integrating the reality of the child's disability into family life. It signifies a shift from the question 'Why did this happen?' to 'What shall we do now?'

At this stage, parents may experience the following:

Acceptance is not about passively resigning oneself to the situation, but rather about seeing reality as it is and deciding to move forward with it. The most common manifestations of acceptance and reorganisation are listed below.

Shift in focus on the child: The family stops focusing solely on the child's deficiencies or diagnosis label and begins to focus on their existing abilities, strengths, and individual personality. Instead of saying, 'We are raising a child with autism,' they start using language such as, 'Ege has autism, but he has an amazing musical memory and is very good at matching colours.'

Positive reframing: Instead of viewing the challenges as a disaster or a burden, the family begins to see them as a special mission, an opportunity for growth, or a different path in life. Instead of saying, 'This situation has ruined our whole life,' they begin to say, 'This process has made us a more patient, more compassionate, and more connected family.'

Advocacy & Empowerment: After accepting the situation, the family moves beyond being passive recipients and becomes active advocates for their children's rights. Families actively communicate with local authorities, schools, or healthcare institutions regarding their children's education and treatment, and even join civil society organisations to support other families.

New and realistic expectations: Giving up traditional dreams for the child's future (university, standard career) and setting small, meaningful, individualised goals that match their capacity. Accepting the reality that 'we cannot expect them to become an engineer' and focusing on the goal of 'our aim is for them to acquire the skills to live as independently as possible in the future.'

Reorganisation refers to the practical and structural changes that follow acceptance. It involves operationally reshaping family life according to the child's needs.

Redistribution of roles and responsibilities within the family: The burden of care is no longer borne by a single parent (usually the mother) but is shared in a clear and planned manner between the other parent, siblings and extended family. The father regularly taking over physiotherapy exercises in the evenings; the older sibling helping with the communication device used by their sibling or reading to them.

Creating new and functional routines: Creating a flexible but predictable new daily and weekly schedule based on the child's therapy, school and medical needs. Establishing a fixed therapy session on Saturday mornings instead of weekend outings; arranging meal times in a quiet, low-stimulus environment to suit the child's sensory sensitivities.

Active use of support networks: Families actively and systematically using professional and social networks to support themselves and break out of isolation. Regularly attending support groups; arranging a carer (assistant); teaching grandparents childcare skills and receiving regular support from them.

Changing financial planning and priorities: Reallocating the family's economic resources according to the child's priority needs and planning long-term costs. Making budget cuts for additional expenses (e.g. taking fewer holidays); setting up a special savings account or legal guardianship plan for the child's future independent living.

Adapting the home and living space: This involves modifying the physical environment at home to suit the child's needs and safety. Changing door locks to prevent the child from running away; creating a quiet corner (sensory area) at home for children with sensory needs; adding grab bars or ramps in the bathroom for those with limited mobility.

Case study: Consciously restructuring social life

Can is a child with special needs. Can's father said to his wife, 'Next week, we're going to the park with the family of Can's school friend Emre. They don't judge us; on the contrary, we share experiences.' His wife agreed: 'Yes, thanks to that group, we stopped feeling isolated. Getting together with people who understand us, who are like us, gives us strength.'

4.2. Parental Roles and Their Effects

Introduction

This section examines the profound identity changes that occur when a parent becomes the carer of a disabled child.

Role Accumulation Phenomenon

Having a child with special needs fundamentally changes parents' roles, responsibilities, and family dynamics. This is a complex process that leads to both significant challenges and profound opportunities for personal growth. One key concept that explains the intense stress and exhaustion experienced by families with a child with special needs is the concept of '**Role Overload**'. Parents, in addition to being a 'mother' or 'father,' often have to take on multiple new and demanding roles simultaneously. This situation means that the number of roles an individual must fulfil at the same time, or the expectations these roles entail, exceed their capacity.

The Case Manager Role: The phenomenon of 'Role Overload' is a situation frequently experienced by parents of children with special needs. This situation arises when parents take on new, intensive and specialised roles in addition to their normal roles (spouse, mother/father, employee). Among these overlapping roles, being a 'Case Manager' is perhaps the most exhausting and mentally demanding.

Even if the parent is not an official case manager, they become the central person managing the child's complex needs. This role encompasses the coordination, planning, and follow-up tasks that a professional would perform.

Managing the Constant Communication Network: Parents must constantly maintain communication between all the professionals in their child's life (doctors, physiotherapists, speech therapists, psychologists, school administrators, special educators, etc.).

Controlling the Flow of Information: Continuously updating medical reports, therapy notes, and education plans to ensure each specialist is aware of what the others are doing.

Parent Language: ‘I need to tell the speech therapist today what the physiotherapist suggested yesterday so that they can adjust the session accordingly. The school should also be aware of this new information.’

Appointment and Transport Planning: Organising all appointments (often on different days and in different places), arranging transport, and adjusting care for siblings accordingly.

Financial and Legal Planning: Filling out insurance forms, tracking therapy fees, and handling paperwork for legal entitlements (reports, early retirement, assistance).

Parent Language: ‘If I don't fill out the insurance form with the correct codes, they won't pay for this month's therapy fees. Also, if I schedule that doctor's appointment for 9:00 a.m., who will pick up the older girl from nursery?’

Deciding on a Treatment Protocol: Deciding on the most appropriate course of action from countless opinions and treatment options regarding the child's condition. This creates significant pressure and responsibility.

Monitoring Service Quality: Continuously evaluating the quality of services provided to the child and, when necessary, objecting or changing service providers.

Parent Language: ‘Is this dietitian's recommendation correct? Or is the medication the other doctor suggested better? I'm not a doctor, but I have to make this decision, and I'm very afraid of making the wrong one.’

Medical Expert Role: One of the many demanding roles that parents of children with special needs take on within the phenomenon of ‘Role Accumulation’ is the role of ‘Medical Expert’. This role means that the parent has a deep understanding of the medical and therapeutic information related to their child's condition, often becoming more knowledgeable than professionals.

Extensive Research: From the moment the child is diagnosed, parents spend hours gathering information from articles, scientific studies, forums, and treatment options. They become proficient in medical terminology related to the condition, genetic risks, and possible accompanying illnesses.

Second Opinion Seeker: Not satisfied with the opinion of a single doctor or therapist, they constantly research the latest treatment methods or tests.

Parent Language: "I lie awake at night Googling every letter of my child's syndrome. Now I know publications that some doctors don't even know about. I've become the little scientist of the house."

Supervision by Specialists: Parents learn the techniques used by physiotherapists, speech therapists, and special education specialists and are responsible for performing these exercises at home. They turn their home into a mini-rehabilitation centre.

Medication Management: They monitor the dosages of medications used, their potential side effects, and interactions, and manage the medication schedule accurately.

Parent Language: 'I am no longer just a mother; I am also the speech therapist's assistant, the Sensory Integration Specialist's home practitioner. No one knows better than me which exercises to do, when, and for how long. All this responsibility goes far beyond normal parenting.'

Providing Education: Parents are forced to personally explain their child's special needs, sensitivities, and the methods that work best for them to new doctors, teachers, or carers who are not sufficiently familiar with the child's condition.

Correcting Misdiagnoses: Sometimes they feel the need to identify a medical professional's incorrect or incomplete diagnosis and steer them in the right direction.

Parent Language: 'I have to tell the whole story from the beginning to every new school, every new doctor. It's as if I'm lecturing them. I have to say, "No, doctor, this symptom is not related to that, we've tried that". I am the manager and expert of my own child's file.'

Advocate Role: This role means that the parent is the person who fights, negotiates, and persists on behalf of the child in every area, from the child's most basic needs to their most complex legal rights. It refers to the role of fighting for services, inclusivity, and rights within the education and healthcare systems. The Advocate Role is the most significant factor intensifying role overload because:

Constant External Struggle: While other roles (care, therapy) are within the home, the advocate role places the parent in constant conflict and tension with external systems (school, bureaucracy, healthcare system). This creates a never-ending state of defence.

Bureaucratic Burden: This role requires time-consuming and energy-sapping tasks such as extensive paperwork, form filling, telephone calls, reading legal texts and attending meetings.

This mental burden completely consumes the energy the parent would otherwise devote to other roles (spouse, personal self).

High Risk and Anxiety: Parents carry the anxiety that if they do not perform this role well enough, their child's education, health, and future will be jeopardised. This leads to an excessive sense of responsibility and chronic stress.

Emotional Toll: Every rejection, every objection that is turned down, or every bureaucratic obstacle increases the parent's feelings of anger, disappointment, and injustice.

Therapist Role: This role requires the parent to transform the home environment into a rehabilitation centre or educational space, to constantly apply the techniques used by specialists, and to meticulously monitor the child's development. The role of 'Being a Therapist' is more demanding than other roles because:

Change in Parent-Child Relationship: This role can get in the way of the parent's natural, relaxed, and unconditional love-based relationship. As the parent constantly becomes a performance-oriented educator, the time spent with the child may feel like 'teaching' or 'practising'.

Emotional Burden: When the parent does not see sufficient progress in their child's development, they blame themselves and feel like a failed therapist (Guilt phase).

Blurring of Boundaries: 'Work' moves into the home. The concept of working hours disappears; due to sleepless nights, weekend therapy sessions, and constant data recording, the parent's rest and personal time disappear.

Taking on the Burden of Professionals: Parents are forced to take on the work of professional experts, who charge high fees and have limited availability, free of charge and on a full-time basis. This may cause parents to give up their own careers.

The Effects of Role Changes

The most destructive consequences of role overload and the new parental roles that come with having a child with special needs are defined in the literature as Caregiver Burnout (e.g., Maslach Burnout Inventory) with three components: Emotional exhaustion, depersonalisation, and reduced personal accomplishment.

Emotional Exhaustion: Emotional exhaustion goes beyond simply 'feeling sad' and manifests in concrete ways that impair a person's daily functioning:

Depersonalisation: The parent becomes emotionally unresponsive towards their child, spouse, or other family members.

Expression: Displaying a blank stare in situations that used to make them sad or happy. Inability to respond emotionally to their child's successes or difficulties.

Reduced sense of achievement: The parent feels inadequate no matter how hard they try (in therapist, lawyer, or manager roles).

Expression: Constant thoughts such as 'Nothing I do is enough' or 'I am not a good parent' (increases feelings of guilt).

Restlessness and irritability: Because emotional reserves are depleted, even minor stressors cause significant reactions.

Expression: Experiencing sudden and intense outbursts of anger even in situations that would normally be met with patience.

Physical symptoms: The body converting mental and emotional exhaustion into physical ailments.

Expression: Constant headaches, stomach problems, muscle tension, and frequent illness (weakened immune system).

Personality Disorder: The intense 'Role Overload' and constant role changes that come with having a child with special needs can trigger existing personality disorders in parents, exacerbate their symptoms, or seriously affect their ability to cope. This situation is a direct result of the chronic stress, sleep disorders, social isolation, and financial burden associated with raising a child with special needs.

The potential effects of role changes, particularly on personality disorders:

Effects on Borderline Personality Disorder (BPD): BPD is characterised by intense emotional swings, unstable relationships, and fear of abandonment.

Effects on Avoidant Personality Disorder: This disorder is characterised by avoidance of people due to fear of social rejection and feelings of shame.

Effects on Narcissistic Personality Disorder: This disorder is characterised by a belief that one knows everything, a need for admiration, and a lack of empathy.

Decrease in Personal Achievement: A decrease in personal achievement among parents of children with special needs usually arises as a result of the parent directing all their energy and focus towards the child's needs. This situation causes the individual to drift away from their own identity and goals. The decline in personal achievement is not limited to career success; it also encompasses the parent's decline in personal development, social life, and personal goals.

This decline in personal achievement has profound emotional consequences for parents:

- *Disappointment:* Lasting disappointment caused by the gap between the life they once dreamed of and their current life.
- *Feeling of worthlessness:* Parents who have left their jobs in particular may feel worthless, as they feel disconnected from social production (this intensifies the guilt phase).
- *Anger Towards Spouses:* When one spouse continues their career and the other is forced to quit, it can create jealousy, unfairness, and hidden anger in the relationship..

Tension in Marriage/Partner Relationships: The intense role overload that comes with having a child with special needs is a major source of pressure and tension, particularly on marriage and partner relationships. Parents stepping outside their traditional roles and taking on new, demanding roles (lawyer, therapist, manager, etc.) disrupts the balance between partners and triggers conflicts. The most common forms of tension created by role changes in marriage/partner relationships are:

The Unequal Distribution of Caregiving Burden

- **Role Segregation:** Typically, one partner (usually the mother) assumes the role of 'Primary Caregiver/Therapist,' while the other partner (usually the father) focuses on the role of 'Financial Provider/Advocate.'
- **Form of Tension:** The partner bearing the care burden feels that the other partner is not sufficiently supportive or sensitive. The partner bearing the financial burden is criticised for not fully understanding the emotional intensity of caregiving.

- Result: Emotional distance develops with statements such as ‘You don’t understand’ or ‘The whole burden is on me,’ and feelings of loneliness become apparent between the couple.

Lack of Communication and Constant Crisis Mode

- Change in Content: The couple's topics of conversation shift away from romantic or personal sharing and become entirely child-focused and problem-solving oriented (appointments, therapies, medications, payment plans).
- Form of Tension: Partners begin to treat each other only as a manager or work colleague. Emotional needs and intimacy are pushed into the background. Communication during stressful moments turns into blame and outbursts of anger.
- Result: Emotional avoidance (keeping away from each other) or hostile communication (constant criticism) develops between partners.

Different Coping Strategies

- Strategy Difference: One partner may respond to the situation with denial (shock phase) or intense anger, while the other may tend towards acceptance and immediate problem-solving (reorganisation).
- Form of Tension: Partners judge each other's emotional reactions. For example, one may seek emotional support, while the other tries to offer a practical solution, leading to a feeling of incomprehension.
- Result: Judgement and Feeling of Injustice. Questions such as ‘Why are you so calm?’ or ‘Why are you exaggerating so much?’ deepen the emotional conflict.

Loss of Personal and Marital Time

- Time Constraints: Childcare and therapy programmes completely eliminate the time couples can devote to each other or themselves. The roles of ‘Therapist’ and ‘Manager’ consume all free time.
- Form of Tension: Couples cannot make the effort to maintain their role as spouses. Activities such as sexual intimacy, shared hobbies, or simply relaxing become a luxury, seriously reducing relationship satisfaction.
- Result: The marriage becomes merely a logistical partnership.

Financial Pressure

- Additional Costs: Increased financial burden due to therapies, special education, medical devices, and medication.
- Form of Tension: Money becomes a constant topic of discussion. Pressure increases on the partner who earns money, while the other partner may feel guilty about spending.
- Result: Stress and insecurity, coupled with financial burden, undermine the sense of security in the marriage.

To manage these tensions:

Clarify Roles: Partners should clearly discuss which roles they take on (Who is the Lawyer? Who is the Therapist?) and accept each other's burdens.

Create Regular 'Partner' Time: Set aside periods of time, even if brief, to talk and show interest solely as partners, independent of the children.

Seeking Professional Help: Seek couples therapy to resolve communication issues and develop healthy coping strategies under the guidance of an expert.

Expressing Appreciation: Partners should learn to openly appreciate each other's roles and the effort they put in (the struggle in the Lawyer role, the patience in the Therapist role).

4.3. Balancing Family Roles and Including Siblings

Introduction

This section focuses on Family Systems Theory (Bowen, 1978), which states that a change in one family member affects the entire system. Family Systems Theory enables us to understand that a child with special needs is not merely a 'problem' but a central figure who alters the structure and function of the entire family system. Therefore, support programmes should emphasise not only the child but all subsystems (spouses, siblings, parents).

Strategies for Balancing Roles

Strategies used to protect the spouse/marriage subsystem ensure that the relationship continues beyond the parental role. Implementing the strategies outlined below prioritises the spouse/marriage subsystem, enabling the family to stand stronger as a whole in the face of challenges.

Scheduled ‘us’ time: Regularly set aside periods of time when topics related to childcare or special needs are not discussed. This could be a short coffee break or a hobby. The purpose of us time is to ensure that partners remember each other not only as “caregivers” or ‘parents’ but as spouses.

Small expressions of affection: Do not neglect physical closeness (hugging, holding hands) and verbal expressions of appreciation. When the emotional tank is full, coping with stress becomes easier.

Recognise withdrawal: It is common for partners to distance themselves from each other (emotional or physical withdrawal) when under stress. Recognise this pattern of withdrawal and consciously try to reconnect.

Using ‘I’ language: When expressing feelings and needs, focus on your own feelings rather than blaming your partner (‘You never help’) (‘I feel very tired and need some time alone’).

Set aside time for problem solving: Discuss serious issues concerning the children or financial concerns at a specific time when you are not tired and can give your full attention. Avoid using rest areas such as the bedroom as a place for problem solving.

Listening skills: When your partner just needs to be heard, prioritise listening with empathy rather than offering solutions.

Fair, not equal distribution: Rather than tasks being equal (the same number), ensure they are distributed fairly according to both partners' abilities, schedules, and energy levels.

Avoid the manager role: Avoid one partner constantly telling the other what to do (the manager role). Make tasks and responsibilities transparent using a shared calendar or planning tool.

Seek professional help: Accept outside help (caregiver, extended family, professional support) to reduce the burden of care and do not view this as a weakness. Outside support provides breathing space for the couple's subsystem.

Shared vision: Work together when setting long-term goals regarding the child's future, education, or care. Having a shared vision reduces feelings of uncertainty.

Emotional validation: Do not dismiss your partner's sadness, fatigue, or disappointment. Provide emotional validation with statements such as, 'I know you're struggling, and you're not alone in this.'

Individual self-care: When both partners set aside time for stress management (exercise, meditation, hobbies) on their own, it results in less tension and more resilience for the couple.

Strategies for maintaining individual identity (self-care) are often one of the most neglected but also one of the most critical issues. When parents completely dedicate themselves to their children's needs, they risk becoming trapped in the "parent-only" role. Effective strategies for maintaining individual identity and self-care are outlined below:

Stepping outside of parent identity: Avoid defining yourself solely through your child's care. Remember and cherish your other identities—as spouse, friend, professional, artist, reader, athlete, etc.

Small escape spaces: Create "spaces" (physical or mental) that are solely yours, where the child's condition is not discussed or cared for. This could be a short walk, a coffee break, or a hobby.

Setting aside time (Non-Negotiable Time): Just like therapy appointments or doctor's appointments, add personal time as a visible item on your calendar. This should be regular, even if it's just 30 minutes a week.

Learning to say no: When offered extra responsibilities (school volunteering, social obligations), learn to politely say "no" to protect the limits of your energy and time.

Utilizing a caregiver network: Dedicate time to self-care during periods when a trusted caregiver (spouse, family member, professional caregiver) is looking after the child.

Enough sleep: Chronic insomnia is a major trigger of burnout. Strive to get regular and sufficient sleep as much as possible. If necessary, establish "sleep-in-shifts" with your partner.

Nutrition and exercise: It's easy to turn to fast and unhealthy foods during stressful times. Pay attention to balanced nutrition to keep your energy levels high and regular physical activity (even just a simple stretch or walk) to reduce stress levels.

Mindfulness and relaxation techniques: Dedicate a few minutes each day to breathing exercises, meditation, or simple relaxation techniques. This helps prevent stress from building up.

Therapy and Counseling: Seeking professional help from a therapist or support group is the healthiest way to share emotional burdens and develop coping strategies.

Celebrate Successes: Celebrate small successes in your own life, not just your child's. For example, finishing a book, starting a new exercise, or completing a work project.

Connect with Friends: Maintain regular contact with old friends (people you don't constantly have to talk to about your child's condition). Social support reduces feelings of isolation.

Support Groups: Meeting with other parents who share similar experiences strengthens the feeling of "I'm not alone" and allows you to receive valuable practical advice.

Remember: Just as you need to put on your own oxygen mask first in an emergency on a plane, you need to meet your own physical and emotional needs first in order to continue effectively caring for your child with special needs. Self-care is not selfish behavior, but a necessity that ensures the sustainability of your parenting role.

Involving Siblings in the Process

Within the context of Family Systems Theory, addressing the impact of a child with special needs on siblings and methods of healthily including them in the process is vital for the overall health of the family. They are sometimes called “glass children”; parents ignore them and focus on the needs of their child with special needs.

Having a sibling with special needs creates a unique and complex chain of experiences for other siblings. These experiences include both positive and negative emotions and challenges, and are often masked by the pressure to be a “good” sibling. Common experiences and emotions faced by siblings of children with special needs are expressed below.

Feelings of Neglect and Insufficient Attention: A large portion of parents' time and energy is spent on the care, appointments, and crisis situations of the child with special needs.

Being Overshadowed: Feeling that their own successes or problems are insignificant compared to the needs of their sibling with special needs.

Pressure to "be good": Avoiding expressing their own problems or needs in order to be less of a burden on parents.

Jealousy: Feeling jealous of the intense attention given to the sibling with special needs and feeling guilty because of this feeling. Stress, Anxiety, and Burden: Constant stress and uncertainty within the family affect the mental and emotional health of siblings.

Anxiety about the future: Deep anxiety about who will take responsibility for the sibling with special needs when the parents age or die.

Shame and isolation: Feeling ashamed in social situations because of the sibling's behavior or condition, and therefore avoiding social gatherings or activities.

Role reversal: Taking on more responsibilities than expected for their age (household chores, sibling care), i.e., assuming a "little parent" role.

Guilt and sadness: Siblings often struggle with complex and conflicting emotions.

Living grief: Experiencing a constant feeling of sadness or "chronic grief" stemming from their sibling's lack of normal development.

Guilt: Thinking that their sibling's condition is somehow their own fault, or feeling guilty from time to time due to anger or frustration towards their sibling.

Inequality of opportunity: Feeling guilty for having normal development and opportunities in their own lives.

Positive Experiences and Strengths: Despite the challenges, there are also significant positive experiences that come with having a sibling with special needs.

Empathy and maturity: Developing a high level of empathy in accepting and understanding the differences of others.

Responsibility and patience: Learning to take responsibility at an early age, developing patience and tolerance in difficult situations.

Strong bond: Developing a deep, unconditional bond of love and protection with the sibling with special needs.

Advocacy skills: Becoming skilled and passionate in defending the rights of others.

Conflictual Relationships: The relationship between siblings can become complicated depending on the nature of the challenges.

Conflict: Frequently experiencing arguments or friction due to difficulties in regulating the behavior of the sibling with special needs.

Protectiveness: Feeling an excessive need to protect the sibling from external threats or bullying. It is critical for parents to be aware of these experiences and to validate both the positive and negative emotions of the siblings so that they can grow up healthy.

Inclusion and Support Strategies: Siblings are often individuals who experience family challenges firsthand, but whose emotional needs are frequently overlooked. Strategies for healthily involving siblings and supporting their individual well-being are outlined below.

Open Communication and Honesty: Siblings often feel and understand the situation of their sibling with special needs more than their parents realize. Lack of information, combined with anxiety and imagination, can lead to fear.

Clear Information: Use honest and simple language appropriate to their age to explain the sibling's diagnosis and needs. Do not keep the situation a secret.

Answering Questions: Patiently and openly answer any questions siblings have about the situation (even if they are difficult or emotional).

Validating Feelings: Acknowledge and validate that all feelings the sibling experiences (anger, shame, jealousy, sadness, even the competition that comes with normal sibling relationships) are normal. Use phrases like, "It's okay to feel angry, this is a difficult situation."

Focusing on Individual Needs (Quality One-on-One Time): Siblings may feel neglected due to the intensive care of a child with special needs.

Special Time: Schedule uninterrupted, one-on-one time (even if it's only 15-30 minutes a week) for each sibling, dedicated solely to them. During this time, they should receive full attention, and the special needs sibling's condition should not be discussed.

Privileges (Balancing): To balance the extra attention the special needs child receives, support the individual hobbies or extracurricular activities of the other siblings. Allow them to develop their own identities as well.

Developmental Awareness: Appreciate the developmental challenges and achievements of the sibling appropriate to their age. For example, celebrate their academic success or athletic talent.

Healthy Distribution of Roles and Responsibilities: Avoid putting siblings in the role of "little parent."

Voluntary Participation: Encourage siblings to voluntarily take on tasks related to their special needs sibling (such as feeding, dressing, and taking them to therapy), rather than being obligated to do so.

Setting boundaries: Make it clear that siblings have their own lives and that their responsibility for caring for a sibling with special needs isn't as great as that of parents. Avoid statements like, "You're the older sister, so you always have to take care of them."

Encouraging shared activities: Encourage games or activities that are age- and ability-appropriate, fun, and allow for positive interaction with the sibling with special needs (e.g., drawing together, playing a short game).



Figure 2. *The bond of brotherhood unites hearts, not differences.*

External Support and Peer Groups: Providing an environment where siblings can share their experiences reduces feelings of loneliness.

Sibling Support Groups: Encourage them to participate in support groups where other children with a sibling with special needs come together. This is invaluable for them to share their feelings and see that others are going through similar things.

School Information: With the sibling's permission, inform the school guidance counselor or close friends about the situation. This helps provide the emotional support the child may need at school.

Appreciation and Reward: The patience, understanding, and helpfulness shown by siblings should be appreciated.

Thanking: Sincerely thank your sibling for even the smallest help.

Being a Role Model: As parents, be role models by showing that you cope with stress in a healthy way. Emphasize the importance of seeking help together and family teamwork.

These strategies ensure that siblings can meet their own emotional and developmental needs and be positively involved in the process as they grow up in a family with a sibling with special needs.

4.4. Ethical Principles in Informal Counseling

Introduction

This section focuses on the “Informal Counseling” aspect of your program, teaching parents how to establish and utilize an effective support network.

Creating a Support Ecosystem

Resilience is closely related to the quality of the family's support network. There are many formal and informal support mechanisms available to families with children with special needs as part of the Support Ecosystem Development process.

Formal Support: As part of establishing a Support Ecosystem for families with children with special needs, formal support includes basic medical support, educational support, and community services, generally encompassing the following areas:

Basic Medical Support: This support focuses on managing the child's overall health and specific needs.

Early Diagnosis and Intervention Programs

- o Screening tests and comprehensive assessments to identify special needs at the earliest possible stage.
- o Treatment and education programs initiated immediately after early diagnosis to support the child's development (e.g., newborn screenings, developmental delay assessments).

Primary Health Care and Specialist Follow-up

- o Regular follow-up by the Family Physician/Pediatrician providing the child's general health care (vaccinations, routine check-ups, acute illness treatments).
- o Multidisciplinary medical management in collaboration with specialist physicians from fields such as Neurology, Cardiology, Genetics, and Endocrinology, tailored to the specific needs.

Medication and Medical Treatment Management

- o Provision and monitoring of prescribed medications and medical treatments for the management of symptoms and secondary conditions associated with primary disorders.

Rehabilitation and Therapy Services: These are critical supports aimed at improving a child's functionality, independence, and quality of life.

Physical Therapy and Rehabilitation

- o Focuses on improving motor skills, mobility, and physical functionality.
- o Specialized applications such as kinetotherapy (movement therapy).

Occupational Therapy

- o Helps develop skills and adaptations to increase participation in daily living activities (dressing, eating, personal care, school activities).

Speech and Language Therapy

- o Works on communication, language skills, speech disorders, and swallowing difficulties.

Assisted Technologies and Devices

- o Training on the provision, adaptation, and use of assistive devices such as wheelchairs, prosthetics, hearing aids, and speech support devices..

Mental Health and Psychosocial Support: Services aimed at the emotional and mental health of the child and family.

Child and Adolescent Psychiatry/Psychology

- o Diagnosis and treatment of conditions such as behavioral disorders, anxiety, depression, and attention deficit disorder.
- o Psychological counseling and therapy to help the child and family cope with their special needs.

Family Counseling and Education

- o Training for family members on the nature of special needs, strategies that can be applied at home, and care skills.
- o Creating an environment for sharing information and experiences through Support Groups for Parents.

The scope, funding, and accessibility of these services vary according to the economic level of countries, the structure of the health system, and social welfare models. However, the general trend is to strengthen primary health care services, integrate rehabilitation services into the system, and ensure care coordination. In addition to these medical supports, there are also educational and social/financial supports that will be included in the family's overall support ecosystem.

Educational Support: The individuals involved in educational support are not limited to teachers within the school; they consist of experts who view your child's development from different perspectives.

Special Education Teacher: They are at the center of the process. They develop methods suitable for your child's learning pace and style.

School Counselor (Psychological Counselor): They monitor both your child's and your emotional state and manage social adaptation processes.

Counseling and Research Center (RAM) Experts: This is the team that conducts the official diagnosis and referral processes for your child and decides which school or class they should be in.

Rehabilitation Center Instructors: These are experts who provide support education outside of school hours, reinforcing the child's development at school.

Your Biggest Support Tool: IEP (Individualized Education Program)

The heart of the educational team's support is the IEP. You can think of it like a garment tailored specifically for your child. The standard curriculum may be too tight or too loose for your child; this team comes together to answer these questions:

- What can your child do now?
- What are the goals for this year?
- What methods will be used to achieve these goals?

The Formal Education Team Empowers You in Three Key Areas:

- Provides a Roadmap: Reduces anxiety about "what will happen tomorrow?". Your child's short-term and long-term goals become clear.
- Eliminates Isolation: You will have a professional to consult when you encounter a problem (e.g., a behavioral problem or learning disability).
- Advocacy: Ensures the protection and implementation of your child's educational rights (inclusive education, support education room, etc.).

This support system works at full capacity as long as you are involved. The ecosystem operates on a simple cycle:

1. Observation: The teacher observes the child at school, and you observe the child at home.
2. Sharing: These observations are combined in regular meetings (such as IEP meetings).
3. Implementation: You are taught how to reinforce a skill learned at school at home.

4. Updating: Goals are updated as your child progresses.

Remember: You are the "HONORARY PRESIDENT" and the most important member of this team. Experts may have technical knowledge, but you are the one who knows your child best..

Community Services: Think of this ecosystem as a whole of formal and social opportunities offered to lighten your family's burden and help your child integrate into society.

Economic and Social Support (Financial Relief): This is the most tangible aspect of community services. Support systems implemented worldwide for parents of children with special needs aim to alleviate the financial and psychosocial burden on the family.

Economic Support (Financial Assistance): Economic support is designed to cover the additional costs required for the child's care and education.

Direct Cash Assistance: In many European countries (e.g., the Disability Living Allowance in the UK), a monthly payment is made to the family to cover the costs of care, regardless of the child's degree of disability.

Caregiver Allowance: A salary support provided by the state if a parent leaves their job or reduces their working hours to care for the child.

Tax Advantages and Exemptions: Deductions made from the family's total income, such as income tax reductions. **Excise Tax and VAT Exemption:** Tax exemptions applied to the purchase of specially adapted vehicles or rehabilitation equipment (common in Turkey, Germany, and the USA).

Health and Equipment Financing: 100% or higher coverage of high-cost needs such as wheelchairs, hearing aids, or speech therapy by state insurance.

Social Support (Services and Rights): Social support focuses on improving the family's quality of life and preventing social isolation.

Respite Care: Temporary care (from a few hours to a few days) of a child by professional caregivers so that parents can rest or attend to urgent matters. In Scandinavian countries, this is defined as a "citizenship right".

Inclusive Education and Early Intervention: The child's access to education alongside peers (inclusion) and free special education/rehabilitation opportunities at an early age.

Labor Law Facilitations: Flexible working hours and legal leave rights for parents for therapy or hospital appointments. Early Retirement: Granting mothers with disabled children the right to retire earlier by providing them with premium support for a certain period (a model implemented in Türkiye).

Informal Support: Family and friends are involved in this system. They often want to help, but don't know how. The key is to teach parents to be specific (e.g., instead of “I need help,” say “Can you do the grocery shopping?”).

Parent-to-Parent Networks: The literature consistently shows this to be one of the most effective buffers against stress. Connecting with “understanding” parents reduces isolation and provides practical, experience-based advice.

Counseling and Information Sharing

Having a child with special needs often means a never-ending learning process and a constant flow of information. When seeking information and advice from other parents or experts, managing this process effectively, both emotionally and practically, is crucial. This involves effective communication, both as the person receiving support and the person providing it.

Here are some effective communication strategies you can use as the person receiving support during this "informal counseling" process:

Clarify Information by Asking the Right Questions: Instead of being a passive listener, be an active explorer focused on your own needs. To adapt the other person's experience to your own situation, you can ask questions like:

Elucidation: "At what stage did you find it most difficult to apply this method?"

Making Connections: "What were your child's reactions during that period? Does it show similarities to my child's [specific behavior]?"

Results Focus: "How long after applying this advice did you observe a change?"

Active Listening and Note-Taking: In moments of high emotional intensity, it's very easy to forget or misunderstand valuable information.

Eye Contact and Acknowledgment: Making the other person feel listened to increases the depth of communication.

Note Key Points: During or immediately after the interview, jot down any names, institutions, or methods you find important.

Reflect: Confirm your understanding by saying, "So you're saying that [X] therapy isn't as effective as [Y] in terms of social skills?"

Filter the Information Through Your Personal Filter: Every child is unique, and what works well for one may not work for another. When seeking advice, use these three filters:

Scientific Basis: Is this advice based on medical or educational grounds, or is it simply an individual observation?

Applicability: Is it suitable for our family structure and economic means?

Child's Needs: Is my child's temperament and current developmental level ready to accept this advice?

Set Boundaries and Maintain Emotional Balance: Sometimes, even with good intentions, "unsolicited advice" can be exhausting. In this situation, don't hesitate to set gentle but clear boundaries:

Gentle Stop: "Right now I just need to share and be heard, I'm not really ready for advice, thank you."

Shifting Focus: "Thank you for the information, I'll discuss this with our doctor/teacher. How are you coping with your own fatigue during this process?"

Remember: Every piece of information you receive is an option, not an order. Knowing that you are in control makes you feel more competent.

As a parent of a child with special needs, providing support to another parent is invaluable "peer support." However, this role requires sensitivity and balance. A method that is a "miracle" for you might be a disappointment for another family.

Here are some basic principles to strengthen communication and deepen empathy when you are the one providing support (advice):

Create "Space" Before Giving Advice: Often, what parents need is not technical information, but to feel understood. Before you begin to share information, follow these steps:

Active Listening: Listen without interrupting, simply by making them feel your presence.

Feeling Validation: Acknowledge their feelings with phrases like, "This seems really exhausting, I understand," or "The anxiety you're feeling right now is very human." Ask for Permission: Always ask before giving advice: "We went through a similar situation, would you like me to share a few things that helped us, or would you prefer me to just listen?"

Use "I" Language: When giving advice, speak like a companion, not an authority figure. Statements containing definitive judgments can evoke feelings of guilt or inadequacy in the other person.

Phrases to Avoid	Phrases to Preferred
"You should never give up on this therapist."	"We benefited a lot from this therapist; you can check it out too if you'd like."
"You should start dieting immediately."	"If you're researching dieting and would like to hear about our experiences, I can tell you about them."
"You're doing it wrong, this is the right way."	"We tried method [X] in a similar situation and it gave us the following result."

Remember that Every Child is "Unique": When describing your own child's success, emphasizing that this isn't a general rule reduces pressure on the other person.

Highlight Differences: Leave room for flexibility by saying, "Every child and every family dynamic is different; this method that works for our child may work differently for you."

Be Realistic: Share not only successes but also moments of failure or difficulty. This sharing makes you more approachable and genuine.

Offer "Concrete" and "Small" Support: Sometimes the best advice isn't about giving information, but about making life easier. Instead of saying, "Call me if you need anything," offer concrete solutions:

"You have a hospital appointment tomorrow, if you want, I can pick up your other child from school."

"I heard of an expert in this field, would you like me to share their phone number with you?"

Respect Professional Boundaries: You are a parent, not an expert (doctor, therapist, special education teacher).

When sharing your experiences, be sure to add the note, *"Of course, you will make the most informed decision in consultation with your doctor."* Avoiding medical advice is critical for both your and the other parent's safety.

Remember: A good support system isn't about telling the other parent what to do; it's about providing the emotional support and tools they need to find their own way..

Questions and Answers

1. What stage does the state of being overwhelmed and frozen, experienced by a family when they first learn that their child has special needs, represent?

- A. Bargaining
- B. Anger
- C. Acceptance
- D. Shock

2- Which of the following is a behavior that a family might exhibit during the 'Acceptance' stage?

- A. Blaming the specialists who made the diagnosis
- B. Trying to hide the child's disability
- C. Starting to research education and support services
- D. Constantly expecting a miraculous recovery

3- When parents are forced to act as their child's therapist or special education teacher (case manager role), what are the most common situations this can lead to within the family?

- A. Complete breakdown of the emotional bond between parent and child
- B. Increased role confusion and parenting stress
- C. Spontaneous improvement in family communication
- D. Rapid increase in the child's independence

4- Which of the following is something parents should do to ensure the healthy integration of a typically developing sibling into the developmental process?

- A. Postponing all other needs and focusing on the child with special needs.
- B. Communicating with the sibling only when informed about their sibling with special needs.
- C. Discussing the situation of the child with special needs secretly from the sibling.
- D. Spending regular one-on-one quality time with the typically developing child.

5- As a supportive parent, which approach is more 'empowering' when approaching a family with a new diagnosis?

- A. Just listening and making them feel you're there when they need you.
- B. Immediately listing a bunch of doctors' names and treatment methods.
- C. Constantly showing them how sorry you are.
- D. Constantly talking about your own child's successes.

Answer Key: (1-D, 2-C, 3-B, 4-D, 5-A)

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