

PAGE 2 (Front)

CARING FOR CAREGIVERS:

*A BASIC GUIDE FOR WELLBEING OF PARENTS AND CAREGIVERS OF CHILDREN AND PERSONS
WITH DISABILITIES*

First Edition, December 2023

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*“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers., and those who will need a caregiver”
Rosalyn Carter*

It’s just a matter of time.

FORWARD

Ability Bhutan Society (ABS), in collaboration with UNICEF Country Office has the honour to present this comprehensive handbook on “*Caring for Caregivers*” - *A basic guidebook for wellbeing of parents and caregivers of the children and persons with disabilities.*

Caregiving is journey that demands immense love, compassion, commitments, patience, dedication and resilience for days, months and years. Raising a child in general and a child with disability(s) in particular, have a significant impact on the livelihoods of the parents, caregivers and the entire family on daily basis. However, every parent loves their children and worry about how best they could take care to ensure both emotional and physical well-being of the child, until they attend the adulthood. In the process, they neglect themselves so much that their lives revolve around children, leaving a very little time to take care of their own health and wellbeing, either as a couple or an individual. As parents & caregivers, they are required to sacrifice a great deal of time and expenses, and sometimes even their relationship for the sake of the child. ABS as an intervention center understand that the caregivers as human have basic daily needs like anyone of us and therefore, they need to internalize the importance of knowing how to take care of themselves, and also learn to seek advice from health personnel and others at regular intervals, so that they remain strong & healthy to continue giving the best care to their loved ones as required.

We are also aware that the parents of the children with disability (CWDs) have additional responsibilities and experience more stress than those with normal children. On the other hand, children being innocent, doesn't really appreciate what parents & caregivers have done or doing for them, with or without the burden of stress. Moreover, a number of parents of the CWDs visiting ABS center today are the single parents, without any reliable source of income for their livelihoods. However, they keep hoping that the children would realize it one fine day and at least learn to say Thank You for all their sacrifices. Other sources contributing to stress, are their low self-efficacy, physical demands for caregiving, perceived social exclusion, frequent behavioural change in child, not receiving much support from others around them and their concerns about the future of the child. Therefore, ABS with support of the UNICEF produced this guidebook, specially designed for the caregivers & parents, incorporating the best international practices that suits to our context, and the practical insights from the caregivers themselves, including the real time experiences in nurturing and raising their own children for so long. We would sincerely like to thank them for their invaluable contributions towards making this guidebook practical and user-friendly.

We are hopeful that the caregivers in general, and those parents of the children with special needs, availing direct interventions at ABS in particular, will make the best use of this handbook to take care of their own health and wellbeing and also help them improve their daily living skills in parenting a child, thereby creating a difference in doing things in their everyday life. For an administrator of a child-care center like myself, I will feel nurtured if this handbook, help them to take care of themselves, make them feel better, and bring smiles on the face of each and every stressed-out parent and caregivers, over the years.

On behalf of the ABS family, I would like to convey our sincere gratitude to the UNICEF for their continued support and financing publication of this essential guidebook right on time. It will go a long way towards improving the overall health and wellbeing of the caregivers, parents and their families of the children with or without disabilities.

Happy New Year and Losar Tashi Delek!

Kunzang N Tshering
Executive Director

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Thank you for your contributions!

"Alone we can do so little, together we can do so much" Prof. Helen Keller

Table of Contents

<i>Introduction:</i>	2
<i>Objectives:</i>	3
<i>Chapter 1: Well-being and Self-Care</i>	5
<i>Chapter 2: Psychological Support</i>	10
Counseling and benefits.....	10
Psychological Support Strategies.....	11
Coping with Challenges.....	12
<i>Chapter 3: Taking a Breath: Embracing Caregiver Self-Renewal</i>	13
Benefits of Caregiver Revitalization.....	13
Approaches to Caregiver Revitalization.....	13
Enacting Caregiver Revitalization.....	13
Easing Guilt.....	14
<i>Chapter 4: Skill Development</i>	15
<i>Chapter 5: Inclusive Education and Training</i>	21
Why is Inclusive Education Important?.....	21
How Can Parents and Caregivers Support Inclusive Education?.....	21
Inclusive Education Training for Parents and Caregivers.....	22
<i>Chapter 6: Legal and Rights Awareness</i>	23
Understanding Your Child’s Rights.....	23
Legal Protections.....	23
<i>Chapter 7: Recreational Activities</i>	28
<i>Chapter 8: Accessible Spaces</i>	30
<i>Chapter 9: Community Engagement</i>	34
Why Community Engagement Matters.....	34
Example of Community Engagement in Action.....	34
<i>Chapter 10: Inspiring Journeys of Resilience</i>	35
Triumphing Against All Odds: Bikash’s Inspiring Journey.....	35
Tashi’s Journey: Overcoming Deafness with Determination.....	35
Ugyen’s Vision: Inspiring Brilliance through Blindness.....	36
Passang’s Progress: Triumphing over Autism.....	36
Pem’s Persistence: Conquering Polio with Resilience.....	36
Karma’s Artistic Triumph: Thriving with Down Syndrome.....	37
<i>Reflections from Parents / Caregivers</i>	38
<i>Resource Mapping</i>	40
<i>References</i>	47

Introduction:

Caring for a child with a disability is a journey that demands immense love, dedication, patience and resilience. As parents and caretakers, the role involves not only providing the best care for the child but also ensuring their personal health & wellbeing. This comprehensive guide is designed to offer practical skills, emotional support, and valuable insights to navigate the challenges and joys of parenting a child with a disability. By addressing a wide range of topics, the guidebook aims to inspire and rejuvenate the parents/caregivers, and enable them to create a nurturing environment to empower the children with disabilities (CWDs), which in-turn would also help the caregivers themselves to take care of their health & wellbeing.

Following are some of the definitions drawn from internationally recognized organizations:

World Health Organization (WHO):

- **A caregiver** is a person who provides unpaid care and support to a family member or friend with a long-term illness, disability, or mental health condition.
- **An institutional caregiver** is a person who provides care and support to people living in institutions, such as nursing homes, hospitals, and residential care facilities. This may include providing physical care, such as helping residents with ADLs, as well as providing emotional and social support.

United Nations Children’s Fund (UNICEF):

- **A caregiver** is a person who provides regular and primary care to a child, including providing for the child’s basic needs, such as food, shelter, clothing, and medical care, as well as providing emotional and social support.

International Disability Alliance (IDA):

- **A caregiver** is a person who provides support to a person with a disability, including physical care, emotional support, and help with activities of daily living.

A caregiver in Bhutan is a person who provides care and support to another person who is unable to care of the self, due to disability, age, illness, or other reasons. Caregivers may be family members, friends, neighbors or professionals. It is quite common in Bhutan that many grand-parents are engage as caregivers, often known as the baby sitters of their grand children or grand nephews & nieces, as we still live in an extended family system, taking care of each other.

Objectives:

- **Empowerment Through Knowledge and Skills:** Equipping caregivers with relevant information and resources about various aspects of disability care to make informed decisions. Additionally, empowering caregivers with the skills and confidence to provide effective care for the children with disabilities.
- **Holistic Wellbeing:** Providing strategies and tools to prioritize caregivers’ physical, emotional, and psychological wellbeing.
- **Building Strong Foundations:** Supporting the development of essential skills to enhance the child’s development, education, and overall quality of life.
- **Navigating the System:** Guiding caregivers through the complex landscape of healthcare, legal rights, and financial assistance available for families of children with disabilities.
- **Creating Inclusivity:** Offering insights into fostering inclusive environments, both within the family and in the community at large. Inclusion must begin from home.

- **Finding Joy, Comfort and Balance:** Suggesting ways to engage in recreational activities, find break, and connect with others who share similar experiences.

Each of the topics outlined below shall be explored in detail in the upcoming chapters. Caregivers are reminded that they are not alone; as they live among our close-knit community to support them at every step. By prioritizing caregivers' wellbeing and seeking knowledge, a foundation of strength and love can be created through such nurturing environment that would positively impact on lives of both child and the caregivers themselves.

1. Well-being and Self-Care
2. Psychological Support
3. Taking a Breath: Embracing Caregiver Renewal
4. Skill Development
5. Inclusive Education and Training
6. Legal Rights and Awareness
7. Recreational Activities
8. Accessible Spaces
9. Community Engagement
10. Inspiring Journeys of Resilience



Chapter 1: Well-being and Self-Care

Taking care of yourself is essential for providing effective care for your child with disabilities. Every family's situation is unique, and parents navigate their circumstances in ways that align with their living conditions. It's not uncommon for some parents to experience emotions like grief, embarrassment, or shame when raising a child with a disability. However, it's important to remember that every human being is equal, and children with disabilities deserve respect and dignity. There is no reason to feel ashamed or embarrassed about your child's disability.

To navigate these emotions and promote self-care, it's crucial for caregivers to focus on acceptance. Acceptance is a crucial aspect of self-care for caregivers of children with disabilities. It means coming to terms with your child's disability and embracing them for who they are. Acceptance doesn't mean being happy about your child's disability, but it does mean accepting it as part of their life and yours.

Acceptance can be a difficult journey, but it is essential for your own well-being and your child's. When you accept your child's disability, you can start to focus on their strengths and abilities, rather than their limitations. You can also start to develop realistic expectations for your child and yourself.

Here are some ways for accepting your child's disability:

- Educate yourself about your child's disability. The more you know, the better equipped you will be to handle the challenges and embrace the joys and comfort.
- Talk to other caregivers of children with disabilities. Talking to other parents and caregivers who are going through the same thing can be a source of support and understanding.
- Seek professional help if needed. A therapist or counsellor can help you to work through your emotions and develop healthy coping mechanisms.

While acceptance is a crucial aspect of self-care for caregivers of children with disabilities, it is not always easy to achieve. In the journey toward acceptance, having access to support from family, friends, professionals, and other caregivers can make a big difference in helping caregivers embrace their child's disability and cope with the challenges it brings. This support network not only aids in acceptance but also plays a vital role in prioritizing self-care, which contributes to improved physical and mental well-being. Neglecting self-care can result in stress, irritability, negative thought patterns, fatigue, and disruptions in sleep. These factors can significantly impair your ability to actively participate in daily activities and meet your child's care needs

Table 1: Self-Care Practices

Self-Care Practice	Positive Impact on Well-being	Practical Examples
Physical Activity	Boosts energy, improves mood, and enhances physical health.	Taking a daily walk, stretching exercises, light yoga.
Restful Sleep	Rejuvenates the body and mind, supporting overall well-being.	Establishing a consistent sleep schedule, creating a comfortable sleep environment.
Rest and Relaxation	Promotes relaxation, reducing stress and tension.	Engaging in deep breathing exercises, taking short breaks during the day.
Emotional Expression	Allows for emotional release.	Keeping a journal, talking with a friend or support group.
Spiritual Practice	Offers solace, inner peace, and a sense of connection.	Meditation, prayer, engaging in nature walks.
Open Communication	Releases emotional tension, promotes understanding, and connection.	Having heart-to-heart conversations with a loved one.
Emotional Release	Provides a healthy outlet for emotions, reducing emotional burden.	Engaging in creative activities, such as painting or writing.
Gratitude Practice	Cultivates a positive outlook and enhances overall satisfaction.	Making a daily gratitude list, expressing appreciation to others.
Positive Thinking	Shifts mindset from negative to positive, fostering resilience.	Practicing affirmations, re-framing negative thoughts into positive ones.

A large body of scientific research supports the benefits of self-care for both physical and mental health. For example, a meta-analysis of 148 studies found that regular physical activity was associated with a significant reduction in the symptoms of depression and anxiety. Similarly, a study of 90 adults found that a relaxation program led to a significant reduction in stress levels and an improvement in mood.

In addition, research has shown that self-care practices such as emotional expression, spiritual practice, and gratitude can also have a positive impact on well-being. For example, a study of 200 adults found that those who expressed their emotions in a healthy way were less likely to experience symptoms of depression and anxiety. Another study of 700 adults found that those who engaged in spiritual practices were less likely to experience symptoms of depression and anxiety and had a higher overall sense of well-being. Additionally, a study of 200 adults found that those who kept a gratitude journal experienced a reduction in depression symptoms and an improvement in mood.

Finally, research has also shown that positive thinking can be beneficial for mental and physical health. For example, a study of 150 adults found that those who practiced positive thinking experienced a reduction in stress and an improvement in mood.

Overall, the scientific evidence is clear that self-care is important for both physical and mental health. By engaging in self-care practices, you can improve your mood, reduce stress, boost your energy levels, and enhance your overall well-being.

Making All the Difference: Shifting from negative self-talk to positive language can profoundly impact the well-being of caregivers. For example, changing “I can’t handle this anymore” to “I’m facing challenges, but I’m capable of finding solutions” empowers caregivers to view obstacles as opportunities for growth. This change in perspective fosters resilience and self-confidence, enabling them to tackle difficulties with a proactive mindset.

Similarly, transforming “it’s all my fault my child has a disability” to “disabilities are not caused by blame” eliminates self-blame, allowing caregivers to focus on advocating for their child’s needs without carrying unnecessary guilt. This shift in thinking encourages self-compassion and acceptance, positively influencing both mental and emotional health.

By adopting positive language and thoughts, caregivers reframe their experiences. Recognizing their efforts, connecting with others, and celebrating small victories can lead to improved self-esteem, reduced isolation, and increased optimism. The power of language lies in its ability to shape perceptions and attitudes, ultimately transforming the caregiving journey into one characterized by strength, resilience, and a greater sense of well-being.

Table 2: The power of positive affirmations

Negative Thoughts	Positive Language	Making All the Difference
I can’t handle this anymore.	I’m facing challenges, but I’m capable of finding solutions.	Shifting from despair to empowerment boosts resilience. ¹
It’s all my fault my child has a disability.	Disabilities are not caused by blame.	Removing self-blame fosters self-compassion and acceptance. ²
I’m alone in this struggle.	I have a support network I can reach out to.	Seeking help cultivates a sense of community and reduces isolation. ³
I’m not doing enough for my child.	I’m doing my best to provide love and care.	Recognizing efforts promotes self-esteem and reduces guilt. ⁴
We are a diverse family with many strengths, including my child’s disability.	We’re a unique family with diverse strengths.	Focusing on strengths cultivates a positive family identity. ⁵
I’m not qualified to provide appropriate care and services	I can learn and adapt to support my child’s growth.	Embracing a growth mindset encourages skill development. ⁶
No one understands what I’m going through.	I can connect with others who share similar experiences.	Sharing experiences leads to empathy and mutual support. ⁷
My child will never lead a ‘normal’ life.	My child’s progress is unique and meaningful.	Celebrating small victories enhances optimism and hope. ⁸
I just don’t have time for myself	It’s important to prioritize self-care for everyone’s well-being.	Valuing self-care improves mental and physical health. ⁹

¹ Tedeschi, R. G., & Calhoun, L. G. (1995). Posttraumatic growth: Positive changes in the aftermath of crisis. Psychology Press.

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⁴ Lakin, J. L. (2013). Parenting your child with autism: Raising a happy, healthy child. Routledge.

⁵ Turnbull, A. P., Turnbull, H. R., & Turnbull, R. (2004). Families, professionals, and exceptionality: Preserving culture, promoting resilience. Pearson.

⁶ Dweck, C. S. (2010). Mindset: The new psychology of success. Ballantine Books.

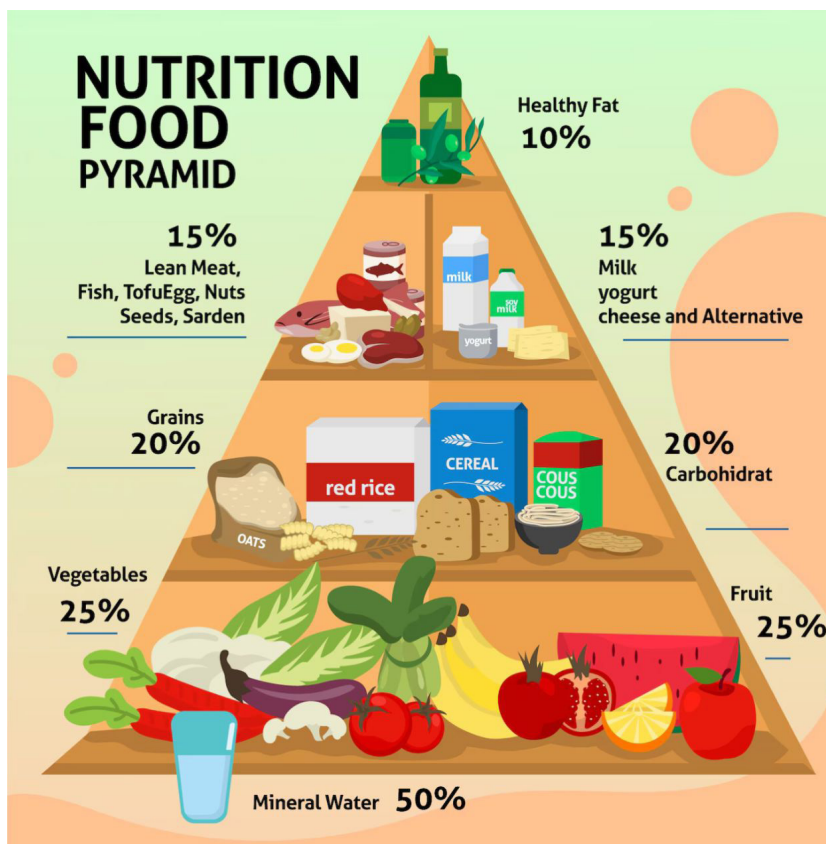
⁷ Gable, S. L., & Reis, H. T. (2010). The science of well-being. Guilford Press.

⁸ Brown, B. (2012). Daring greatly: How the courage to be vulnerable transforms the way we live, love, work, and parent. Avery.

Nutrition Tips:

Some tips for parents and caregivers of children with disabilities on how to improve their own nutrition:

- Eat a variety of foods from all food groups. This includes fruits, vegetables, whole grains, lean protein, and healthy fats.
- Choose fresh and seasonal foods, whenever possible. Self-cooked & fresh foods are more nutritious than processed and well packed foods.
- Limit processed foods, sugary drinks, and unhealthy fats. These foods can contribute to weight gain and other health problems.
- Water is essential for good health. As 60% of our body is made up of liquid, drink plenty of water. Nutritionist advise us to take at least 2 litres of water every day.



“It is health that is real wealth and not pieces of gold & silver” Mahatma Gandhi –

“Came from a plant, eat it; was made in a plant, don’t” Michael Pollan, Author & Journalist

Remember that:

When diet is wrong, medicine is of no use.

Chapter 2: Psychological Support

Raising a child with a disability can be a rewarding but challenging experience. Parents and caregivers often face a range of emotions, including joy, frustration, stress, and even guilt. It is important to acknowledge these emotions and understand that they are a natural part of the journey.

Self-care is essential for parents and caregivers of children with disabilities. It is important to prioritize your own needs, both physically and emotionally. This may mean taking some time for yourself each day, even if it is just for a few minutes. It may also mean asking for help from others when you need it.

There are a number of resources available to support parents and caregivers of children with disabilities. One of the most important resources is counselling. Counselling can provide a safe and supportive space for parents and caregivers to talk about their experiences and to receive support from a trained professional. Counselling can also help parents and caregivers to learn coping skills, improve communication skills, make better decisions, and improve their overall well-being.

Counseling and benefits

Counseling, a form of talk therapy, offers individuals a valuable avenue to tackle their problems and address their concerns. It operates as a collaborative endeavor between a counselor and a client, where the counselor fosters a safe and supportive environment for the client to delve into their thoughts, emotions, and behaviors.

The benefits of counseling encompass:

1. **Stress and Anxiety Reduction:** It aids in alleviating stress and anxiety.
2. **Enhancing Mood and Self-esteem:** It contributes to an improved mood and heightened self-esteem.
3. **Coping with Complex Emotions:** It assists in effectively coping with challenging emotions.
4. **Development of Problem-solving Skills:** It facilitates the development of problem-solving skills.
5. **Enhanced Decision-making:** It supports better decision-making processes.
6. **Improved Relationships:** It fosters improved interpersonal relationships.
7. **Healing from Trauma:** It plays a role in healing from traumatic experiences.
8. **Managing Chronic Pain:** It helps in managing chronic pain.

Particularly for parents and caregivers of children with disabilities, counseling proves to be an invaluable resource. These individuals often encounter unique challenges, including stress, anxiety, guilt, and isolation. Counseling, as recommended by the *American Psychological Association*, offers them the following specific advantages:

1. **Emotional Support:** It provides a secure and empathetic space for parents and caregivers to openly discuss their experiences and receive guidance from trained professionals.
2. **Coping Skills:** It equips parents and caregivers with effective coping mechanisms to manage stress, anxiety, and other complex emotions.

3. **Enhanced Communication:** It aids in improving communication with their child, partner, and other family members and professionals.
4. **Informed Decision-making:** It assists parents and caregivers in making informed decisions regarding their child's care and education.
5. **Overall Well-being:** It contributes to the enhancement of their physical and mental well-being, ultimately leading to an improved quality of life for both themselves and their child.

For parents or caregivers of children with disabilities thinking about counseling, it is strongly recommended to take that step. Counseling can serve as a valuable resource, supporting emotional well-being and empowering individuals to be the best parents or caregivers they can be.

(Source: American Psychological Association)

Psychological Support Strategies

- **Counseling and Therapy:** Engaging with professional counselors or therapists who specialize in dealing with the emotional challenges of raising a child with disabilities.
- **Support Groups:** Joining local support groups with fellow parents and caregivers to share experiences, offer advice, and find solace in a community that understands.
- **Mindfulness and Relaxation Techniques:** Practicing techniques like deep breathing, meditation, and mindfulness to manage stress and anxiety.
- **Setting Realistic Expectations:** Recognizing that no one is perfect, and it's okay to ask for help or take breaks when needed.
- **Communication Skills:** Learning effective communication strategies to express needs, concerns, and feelings with family, friends, and professionals.

Coping with Challenges

- **Embracing Change:** Accepting that life's journey has taken a different path and finding ways to adapt and make the most of the situation.
- **Seeking Joy:** Focusing on moments of joy and celebrating achievements, no matter how small.
- **Managing Stress:** Identifying stress triggers and developing strategies to manage them, such as taking short breaks or engaging in enjoyable activities.
- **Balancing Roles:** Navigating the balance between caregiving, personal life, and other responsibilities.
- **Family and Friends:** Relying on the support of loved ones who can provide encouragement, assistance, and a listening ear.
- **Taking Breaks:** Arranging for respite care or temporary relief to recharge and rejuvenate.

Table 3: Different Psychological Support

Strategies for Psychological Support	
Counseling and Therapy	Professional guidance for emotional challenges.
Support Groups	Connection with like-minded caregivers for mutual support.
Mindfulness and Relaxation Techniques	Stress and anxiety management through relaxation.
Setting Realistic Expectations	Reduced pressure, better coping with challenges.
Communication Skills	Effective expression of feelings and needs.
Embracing Change	Adaptation to new circumstances and outlook.
Seeking Joy	Focus on positive moments and achievements.
Managing Stress	Identification and handling of stress triggers.
Balancing Roles	Maintaining equilibrium between caregiving and personal life.
Building a Support Network	Strengthened emotional and practical support system.
Referral mechanism to relevant agencies	If you are being referred, you will benefit from the services of the next office

Chapter 3: Taking a Breath: Embracing Caregiver Self-Renewal

Within the role of a parent or caretaker for a child with disabilities, the significance of the responsibility is unparalleled. While unwavering dedication is admirable, it is imperative to acknowledge that attending to personal well-being is equally vital in the realm of caregiving. In this segment of the wellbeing package, we delve into the concept of “*Caregiver Revitalization*,” capturing the essence of taking deliberate breaks to rejuvenate, thereby ensuring the well-being of both the child and the personal nurturing.

Caregiver revitalization entails creating a deliberate space for temporary stepping away from caregiving responsibilities. This practice is not a sign of vulnerability but rather a testament to strength and recognition of the utmost importance of sustaining personal well-being.

Benefits of Caregiver Revitalization

- **Self-Nourishment:** Caregiver revitalization prioritizes the preservation of physical and emotional health, effectively mitigating the risks of burnout.
- **Reenergization:** Through engagement in taking a break, energy is replenished, enabling the provision of higher care upon return.
- **Better Interaction:** The time invested in personal renewal enriches interactions with the child, fostering deeper engagement and patience.
- **Bigger Support Network:** Caregiver revitalization offers an opportunity for the child to engage with other caregivers, expanding social interactions.

Approaches to Caregiver Revitalization

- **Informal Breaks:** Trusted individuals, such as friends, family members, or neighbors, extend short-term care in familiar surroundings.
- **New Adventures:** The child experiences temporary new environments at a dedicated center or specialized facility.
- **Fun Activities:** Planned trips and things to do help the child grow while also giving a break.

Enacting Caregiver Revitalization

- **Planning:** Carefully scheduling times for renewal ensures caregivers understand the child’s needs and routines.
- **Communication:** Sharing important information about the child’s preferences, routines, and medical requirements with the caregiver is key.
- **Trusted Partners:** Choosing caregivers experienced in helping children with disabilities.
- **Gradual Start:** Beginning with short intervals builds trust between the child and the caregiver.
- **Accepting Help:** Even though it’s tough, entrusting others to care for the child fosters growth for both caregiver and child.

Easing Guilt

It's normal to feel guilty when taking time for yourself. But it's important to realize that prioritizing your own well-being benefits both you and the child. It's a commitment to self-care and shows love and responsibility to the family.

Caregiver revitalization isn't shirking duties; it's a commitment to resilience and dedication. Embracing revitalization strengthens the ability to care for the child. Just as unwavering support is given to the child, self-care becomes an investment in overall well-being and a deep expression of love for the family.



Chapter 4: Skill Development

The role of a parent or caretaker of a child with disabilities is multifaceted. Skill development becomes a vital component, ensuring effective care provision. This section of the wellbeing package concentrates on honing essential skills, thereby empowering individuals to confidently navigate the challenges and joys of caregiving.

Table 4: Empowerment through Skills Development

Skill Area	Description	Why Develop the Skill?	How to Develop the Skill
Effective Communication (verbal and non-verbal)	Master clear communication techniques for effective interactions with family members and service providers	Effective communication fosters understanding, reduces stress, and ensures collaborative care, enhancing overall well-being.	Practice active listening by maintaining eye contact, nodding, and asking clarifying questions. For instance, when discussing your child's development plan, use a warm and encouraging smile to reassure that you are committed to their growth. Maintain an open and relaxed body posture to convey approachability. Share your concerns using specific examples to facilitate comprehensive care. Example: When discussing your child's development plan, ask questions such as, "What specific goals are we working toward, and how can we track progress together?"
Empathy and Active Listening	Develop the ability to understand your child's emotions and practice active listening for better connection.	Empathy and active listening deepen relationships, build trust, and enhance emotional resilience in the face of challenges.	Empathize with your child's emotions. When they're frustrated with a task, respond with understanding: "It sounds like that was really challenging for you." Practice active listening by giving them your full attention and avoiding distractions. Example: When your child expresses frustration, respond with empathy: "I understand that you're feeling frustrated. It's okay to feel that way. I'm here for you."

<p>Adaptive Problem-Solving</p>	<p>Cultivate flexibility in problem-solving, adapting to changing situations and making informed decisions.</p>	<p>Adaptive problem-solving empowers you to navigate complex scenarios, reducing anxiety and boosting confidence.</p>	<p>Adapt your problem-solving approach. If a planned activity is canceled, offer alternatives: “The swimming pool is closed, but how about we have an indoor game instead?” When facing unexpected challenges, brainstorm creative solutions with your child.</p>
<p>Organizational and Time Management</p>	<p>Learn strategies to efficiently balance caregiving, appointments, therapies, and personal commitments.</p>	<p>Effective organization and time management reduce overwhelm, create structure, and provide valuable moments for self-care.</p>	<p>Create a weekly schedule that allocates time for caregiving tasks, work, self-care, and family time. Utilize calendars or apps to set reminders for appointments and activities. Example: Create a weekly schedule that includes designated “you” time. Use alarms or reminders on your phone to stay on track and avoid feeling rushed.</p>
<p>Advocacy and Self-Advocacy</p>	<p>Advocate for your child’s needs while also prioritizing your own well-being through effective self-advocacy.</p>	<p>Advocacy ensures your child receives appropriate care, while self-advocacy safeguards your own mental and emotional health.</p>	<p>Advocate for your child’s needs. If you believe they require additional support in school, communicate your concerns: “I think my child would benefit from a smaller class size to receive more individual attention.” Practice self-advocacy by setting boundaries and requesting support when needed. “Please help look after the children, there is a religious ceremony that I want to attend”, “I have a meeting to attend, help look after the children and I will help you pay for the taxi fares.” “I don’t care what others say but I am going for dancing, or singing”</p>
<p>Stress Management and Self-Care</p>	<p>Implement stress-reducing techniques and self-care activities that help maintain your emotional well-being.</p>	<p>Managing stress and practicing self-care are vital to prevent burnout, enhance resilience, and maintain a positive outlook.</p>	<p>Manage stress through deep breathing exercises. Step outside for a brief walk when overwhelmed and repeat a positive affirmation, such as “It is absolutely acceptable to ask for help/to seek services” Engage in self-care activities you enjoy, like reading or gardening, to recharge. “I can do things, but I also need rest and help” “it’s alright, I will take it slow at my child’s pace and not rush. I will keep my goals realistic”</p>

<p>Conflict Resolution</p>	<p>Equip yourself with conflict resolution skills to navigate disagreements and collaborate for positive outcomes.</p>	<p>Conflict resolution minimizes tension, fosters cooperation, and promotes a harmonious environment for both you and your child.</p>	<p>When addressing conflicts, especially in the realm of resolving differences with your partner, prioritize open communication, mutual understanding, and respecting each other's perspectives. "Let's collaborate to discover common ground and determine what's most beneficial for our child's development while actively working to reduce tension." Make sure to actively listen to each other's concerns and engage in constructive brainstorming to find compromises.</p>
<p>Coping Mechanisms</p>	<p>Develop healthy coping strategies to handle challenging emotions and situations in a constructive manner.</p>	<p>Effective coping mechanisms reduce emotional strain, improve mental health, and allow you to face challenges with strength.</p>	<p>Practice deep breathing exercises when stressed: Inhale for four counts, hold for four, and exhale for six counts. When dealing with frustration, take deep breaths to calm yourself before addressing the situation. Identify activities that relax you and add them into your routine, eg – Zumba, dancing, gym, outing, love for music, camping, picnic. Self-reflection can be a helpful coping mechanism and fostering positive manifestations. Seek inspiration from role models by reflecting on their journeys and success stories. Additionally, try techniques like counting from 1-10 and backward or using trauma tapping meditation (tap three times) to further promote relaxation and stress management.</p>

<p>Learning and adapting</p>	<p>Embrace continuous learning, adapting to new experiences, and fostering personal growth throughout the journey.</p>	<p>Learning and adapting promote a growth mindset, increase confidence, and empower you to tackle new situations with resilience.</p>	<p>Attend workshops related to care giving, peer learning, experience sharing. Reflect on your experiences each day by maintaining a diary – like a self-reflection, note what worked well and what you could improve, fostering continuous growth. Embrace new challenges willingly and seek opportunities for learning. “I get motivated when my child learns new things and keeping track of this helps”, “through experience sharing there is scope for sharing my own experience and also opportunity to learn.” ---- “there are many groups base on your child’s condition, I can learn from them and there are many benefits – products, “my child’s condition is not common in Bhutan and I can learn more from the online forums and even the carry-bag is donated from the group” “fund sharing through live tiktok”</p>
<p>Networking and Resource Utilization</p>	<p>Connect with others for mutual support and utilize available resources to enhance your caregiving skills.</p>	<p>Networking provides a sense of community, helps you learn from others, and allows you to access valuable resources and insights.</p>	<p>Join programs where caregivers share experiences and tips. Attend local support group meetings to connect with other parents facing similar challenges.</p>

Chapter 5: Inclusive Education and Training

Inclusive education and training ensure that all children, including those with disabilities, learn and grow together in the same classroom. For example, imagine a classroom that mirrors our diverse world, where every child's strength shine, irrespective of their differences. It's like creating a place where all students can thrive and contribute.

Why is Inclusive Education Important?

Think of a sports team where players with various skills work together towards victory. Inclusive education functions similarly – it brings children of all abilities together to learn, fostering a diverse and supportive environment. When children learn alongside classmates with different strengths and challenges, they become more understanding, patient, and open-minded. This prepares them for a world ready, work ready and future ready, where cooperation, acceptance and the team spirit are key.

How Can Parents and Caregivers Support Inclusive Education?

As parents and caregivers, your role is pivotal in making inclusive education successful:

- **Open Conversations:** Think of your child's education as a unique puzzle. Share your child's strengths and needs with teachers, addressing any language barriers. This collaboration helps them plan a classroom suitable for everyone.
- **Teamwork:** Just as a team collaborates for success, work closely with the school to create a plan that aligns with your child's learning style. This teamwork lays the foundation for your child's achievements.
- **Advocacy:** Similar to advocating for your child at home, advocate for their needs at school. If challenges arise, partner with the school to find solutions collaboratively. Consider advocating for experience-sharing and advocacy forums at schools and institutions, including conversations with school leadership.
- **Continuous Education:** Attend workshops to gain insights into inclusive education strategies. This knowledge equips you to better support your child's learning journey.
- **Friendship Building:** Facilitate playdates and activities both inside and outside of school to help your child build friendships. This enhances social skills and fosters a sense of inclusion within the classroom community. Consider organizing friendship gatherings between parents and teachers.
- **Stay Connected:** Maintain open lines of communication. Regularly engage with teachers, attend meetings, and share your child's progress. This ongoing partnership enriches your child's learning experience.
- **Interactive Activities:** Engage your child in interactive games and recreational activities to make learning enjoyable and promote social interaction.
- **Celebrate Achievements:** Celebrate your child's achievements, no matter how small. This boosts their confidence and motivation.
- **Equal Opportunities and Flexibility:** Advocate for equal opportunities and flexibility in your child's education. Tailor the schedule and structure to meet your child's specific needs and learning style.

Inclusive Education and Training for Parents and Caregivers

Consider the following practical tools to support your child's inclusive education:

1. **Deep Understanding:** Delve into what inclusive education truly means, its benefits, and how it can positively impact your child's growth.
2. **School Collaboration:** Learn techniques to work closely with teachers, creating a classroom environment that nurtures every child's ability and the potential.
3. **Home Learning Support:** Explore strategies to reinforce classroom learning at home. This extends the learning journey beyond school walls.
4. **Effective Advocacy:** Develop skills to advocate for your child's needs within the school system. Ensure your child gets a fair chance at success.
5. **Problem-Solving Tools:** Discover ways to address challenges that arise in the classroom. This toolkit helps you find solutions that support your child's progress.
6. **Fostering Friendships:** Explore methods to help your child build friendships, enhancing their sense of belonging in the school community.

Engaging in this inclusive education training equips you to champion your child's educational journey, nurture their learning, and contribute to an environment that values diversity and inclusion.



Chapter 6: Legal Rights and Awareness

Understanding your child's rights and legal protections is essential for their well-being and development. This section focuses on empowering parents and caregivers with knowledge about legal rights, ensuring that children with disabilities receive fair treatment, access to necessary resources, and opportunities to thrive.

Legal awareness equips you to secure vital services for your child with disabilities. For instance, advocating for inclusive education and necessary accommodations paves the way for their optimal growth. Moreover, legal knowledge enables you to counter discrimination and inequitable treatment your child may encounter. By advocating for equal opportunities and challenging exclusion, you ensure their fair treatment. Understanding your child's legal rights empowers you to actively engage with educational institutions, healthcare providers, and authorities. This empowerment guarantees effective fulfillment of your child's needs.

Understanding Your Child's Rights

In Bhutan, every child, regardless of their abilities, has the right to an education, healthcare, and a life free from discrimination. The Bhutanese Constitution and international agreements uphold these rights. Recognizing and advocating for these rights is crucial to ensuring that children with disabilities have equal opportunities.

Legal Protections

The constitution of Kingdom of Bhutan

- Article 9 (5) of the Constitution of Bhutan states that the State shall endeavour to provide security in the event of sickness and disability or lack of adequate means of livelihood for reasons beyond one's control.

The Convention on the Rights of the Child (CRC) 1989

The Convention on the Rights of the Child (CRC) is an international treaty that sets out the human rights of all children. It is the most widely ratified human rights treaty in the world, with 196 states parties. The CRC sets out the civil, political, economic, social, and cultural rights of all children under the age of 18. It was adopted by the United Nations General Assembly on November 20, 1989. Bhutan was one of the first nation states to signed the CRC on 4th June 1990, and ratified it on 1st August 1990.

The key objective of the CRC is to promote and protect the rights of all children, regardless of race, religion, nationality, gender, or social status. It guarantees all children with a number of fundamental rights, including the right to:

- Life
- Survival and development
- Non-discrimination
- A name and nationality
- Identity
- Family
- Education

- Health
- Play and leisure
- Culture
- Expression
- Thought, conscience, and religion
- Freedom of association
- Protection from violence, abuse, and exploitation.

The CRC also emphasizes the importance of children's participation in decision-making that affects their lives.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

UNCRPD was adopted on 13 December 2006 by the United Nations and opened for signature on 30 March 2007. The Convention applies established human rights principles from the UN Declaration on Human Rights to the situation of the persons with disabilities (PWDs). Bhutan ratified it on 14 June 2023, with reservations expressed on Four Articles related:

1. Liberty to Movement and Nationality
2. Respect for Home and Family
3. Work and Employment, and
4. Participation in Political and Public Life.

Despite these reservations, Bhutan is committed to implementing the UN-CRC and CRPD, ensuring that all children in the country enjoy their full rights.

Article 23 of the CRC is about the rights of children with disabilities. It states that:

- Children with disabilities have the right to live a full and decent life, with dignity and the opportunity to participate actively in the community.
- Children with disabilities have the right to special care, including access to education, training, health care, and rehabilitation services.
- States Parties shall promote the exchange of information and cooperation in the field of preventive health care and treatment of disabled children.

Child Care and Protection Act of Bhutan (CCPA) 2012

- The CCPA 2012, endorsed by Bhutan on May 25, 2012, is a landmark legislation that provides a comprehensive framework for the care and protection of children in Bhutan. It covers a wide range of issues, including child rights, child abuse and neglect, child labor, and juvenile justice.
- Section 27 of the CCPA specifically states that the Government shall take all necessary measures to ensure the protection and promotion of the rights of persons with disabilities. This includes ensuring that children with disabilities have access to education, healthcare, and other essential services.

Child Care and Protection Rules and Regulations of Bhutan (CCPRR), 2015

- The Child Care and Protection Rules and Regulations of Bhutan, 2015 (CCPRR) is a

set of regulations that provide guidance on how to implement the Convention on the Rights of Persons with Disabilities (CRPD) in Bhutan. The regulations cover a range of areas, including education, healthcare, employment, and social protection.

National Policy for Persons with Disabilities (NPPWD), 2019

- The National Policy for Persons with Disabilities, endorsed by the Royal Government of Bhutan in 2019, is a comprehensive policy that aims to promote the rights and well-being of persons with disabilities in Bhutan. The policy is based on the principles of inclusion, equality, and non-discrimination.
- The NPPWD includes provisions related to education, healthcare, employment, social protection, accessibility, awareness raising and sensitization, data collection and research, institutional strengthening, and monitoring and evaluation.

Ten-Year Roadmap for Inclusive and Special Education in Bhutan, 2019

The Ten-Year Roadmap is a comprehensive plan for implementing inclusive education in Bhutan over the next ten years. It includes a number of provisions on how to identify and support students with disabilities, as well as how to create an inclusive learning environment. For example, the Road-map includes provisions for:

- Training teachers on how to identify and support students with disabilities
- Developing and providing inclusive teaching materials and resources
- Making school buildings and facilities accessible to all students
- Raising awareness of inclusive education among parents and the community

Bhutan Building Resolutions 2018

- The Bhutan Building Resolutions developed by the then Ministry of Works and Human Settlements in 2018 are a set of regulations that govern the design, construction, and maintenance of buildings in Bhutan. The 2018 Resolutions include a number of new provisions on accessibility for persons with disabilities. These provisions require that all new buildings be designed and constructed to be accessible to persons with disabilities.
- The accessibility provisions in the Bhutan Building Resolutions include requirements for:
 - Ramps and accessible entrances
 - Accessible restrooms
 - Accessible elevators and lifts
 - Accessible parking spaces
 - Tactile ground indicators and signage
 - Accessible fire alarms and other emergency systems



Inclusive Education Standards 2017

The Inclusive Education Standards 2017 are a set of standards that define what inclusive education should look like in Bhutan. The standards cover a range of areas, including:

- **Curriculum:** The standards require that the curriculum be inclusive and accessible to all students, regardless of their background or abilities.
- **Assessment:** The standards require that assessment practices be fair and equitable

for all students, and that they provide all students with the opportunity to demonstrate their learning.

- Teacher training: The standards require that teachers be trained on how to teach in an inclusive classroom and how to support students with disabilities.

Penal Code of Bhutan 2004, Chapter 9

Chapter 9 of the Penal Code of Bhutan contains a number of provisions related to disability. These provisions prohibit discrimination against persons with disabilities and impose penalties for harming or exploiting persons with disabilities.

Labour and Employment Act of Bhutan, 2007

The following sections of the Labour Act of Bhutan, 2007 are related to disability:

- Section 61: This section requires employers to make reasonable accommodations for employees with disabilities. Reasonable accommodations are changes to the workplace or work environment that allow employees with disabilities to perform their jobs.
- Section 62: This section prohibits discrimination against employees with disabilities. This means that employers cannot discriminate against employees with disabilities in hiring, promotion, training, or any other aspect of employment.
- Section 63: This section establishes a National Disability Commission that is responsible for enforcing the provisions of the Labour Act related to disability.

Chapter 7: Recreational Activities

Caring for children with disabilities involves important responsibilities, but caregivers also need self-care. Participating in activities rooted in Bhutanese traditions can provide valuable relaxation.

Here are some benefits of such activities:

- **Stress Relief:** Engaging in recreational activities can offer a break from daily routines and promote relaxation. Exploring serene places like Dochula Pass, planting trees, taking forest bath, participating in cleanup drives or circumambulating choeten and lhakhang can bring inner peace.
- **Improved Physical Well-being:** Involvement in physical activities like traditional Bhutanese games, like archery, khuru, dego, soksom, jugdum or yoga amid nature can enhance energy levels and overall health.
- **Enhanced Mental Well-being:** Engaging in religious activities, reading books & literature, songs and laughter, circumambulating choeten and lhakhang can contribute to mental well-being and happiness.
- **Building Community Bonds:** Participating in local cultural events, such as Tshucus or volunteer initiatives, learning traditional dances, or engaging in rituals can foster connections within the community and reduce feelings of isolation.
- **Personal Fulfillment:** Pursuing various art works, (Zorig Chusum), such as painting, carving, sculptures, weaving, embroidery, carpentry, etc. which can evoke a sense of accomplishments.

Caregivers of children with disabilities often share stories of how recreational activities have become a cherished part of their family life. One parent expressed, “My family and I often have karaoke nights at home, which has become a cherished recreational activity for us. What makes it even more special is that we involve our child with disabilities (CWD) in these musical evenings.” Another caregiver reflected on their outdoor adventures, saying, “my son and I both enjoy walking alongside the river, he throws stones into the river. Enjoying recreational activities with my child also motivates and encourages us.” Another parent shared, “my son loves pizza, and we make pizza together – he picks up all the ingredients, and it’s quality time for us.” Another parent further shared, “We have always been trying to teach phonetics to him, we tried many other means but when we just happened to find music, and he caught up with the phonetics really fast.” These stories from caregivers illustrate how incorporating recreational activities into family life not only fosters happiness and connection but also plays a pivotal role in the growth and development of children with disabilities.

There are many benefits and long-term effects while engaging in such activities:

- **Spiritual Nourishment:** Involvement in local festivals and spiritual activities provides inner solace and growth.
- **Stronger Community Bonds:** Participation in community events fosters a sense of belonging and strengthens ties.
- **Holistic Satisfaction:** Balancing caregiving with culturally enriching activities contributes to overall fulfillment.

“People who cannot find time for recreation are obliged sooner or later to find time for illness”
John Wanamaker

Chapter 8: Accessible Spaces

Recognizing the potential challenges associated with establishing accessible spaces, particularly when financial limitations are at play, we acknowledge the importance of cultivating surroundings that facilitate the well-being of both caregivers and children with disabilities. Although substantial transformations may pose difficulties, practical measures can be adopted to make meaningful enhancements within your present setting. This journey explores strategies to construct inclusive spaces while adhering to budgetary considerations:

Table 5: Establishing Accessible Spaces

Practical Steps for Accessible Spaces Within Your Means	What to Do	Why It's Beneficial	Example	Incorporating into Well-Being
Simple Rearrangements	Rearrange furniture and belongings to create clear pathways.	Promotes easy movement, reduces stress and frustration.	Rearranging furniture in the living room allows caregivers and child to move freely, minimizing obstacles during caregiving tasks.	Enhance physical well-being and comfort.
Strategic Storage	Organize belongings to eliminate clutter and free up space.	Creates an organized environment, easier to move around.	By decluttering and storing items in designated bins, caregivers create a neat space where they can navigate effortlessly with their child.	Simplify daily caregiving routines.
Comfortable Seating	Provide cushions or pillows for comfortable seating in a quiet, noise-free environment with soft lighting, minimal crowds, and seating arrangements at eye level for both the parent and child.	Dedicated spot for caregiver-child interaction and relaxation.	Putting soft cushions in a quiet corner makes a comfy spot where parents and children can spend time together without loud noises or bright lights bothering them.	Foster emotional bonding and relaxation.

Natural Lighting	Position furniture near windows for maximum natural light.	Reduces eye strain, creates a cheerful atmosphere.	Positioning a play area near a window provides children with ample sunlight for activities, while caregivers benefit from well-lit surroundings.	Promote positive mood and well-being.
Soft Surfaces	Place rugs or mats in play areas for comfortable play.	Promotes safe play, enhances child's well-being.	Covering the floor with soft rugs ensures children can explore and play comfortably, reducing the risk of injury.	Provide a safe and nurturing environment.
Personal Retreat Space	Designate a corner for relaxation and reflection.	Offers a quiet space for caregiver to unwind.	Setting up a area with a comfortable chair and soft lighting provides caregivers a peaceful spot to relax and recharge.	Encourage self-care and stress relief.
Resourceful Organization	Arrange items for easy access and efficient use.	Reduces frustration, saves time during caregiving tasks.	Organizing baby essentials in labeled bins makes it easy for caregivers to quickly locate items during busy moments.	Simplify caregiving routines and reduce stress. For example, placing portable toilets near the beds for easy access.
Enhanced Safety	Remove potential hazards, ensuring a safer environment.	Minimizes risks, reduces anxiety for both caregivers and children.	Securing heavy furniture to prevent tipping and using corner guards on sharp edges protects children from accidents, easing caregivers' worries.	Prioritize child safety and caregiver peace of mind.

<p>Adaptive Furniture</p>	<p>Integrate adjustable or adaptive furniture.</p>	<p>Enhances comfort, accommodates different needs.</p>	<p>Using a table that can be adjusted to the right height helps children play independently and makes it comfortable for caregivers too.</p>	<p>Foster inclusive and adaptable caregiving.</p>
<p>Personalized Zones</p>	<p>Create zones for specific activities.</p>	<p>Streamlines caregiving tasks, increases efficiency.</p>	<p>Arranging a designated area with all bathing essentials makes bath time more efficient and enjoyable for both caregivers and children with disabilities.</p>	<p>Simplify caregiving routines and reduce stress.</p>

Chapter 9: Community Engagement

In the pursuit of supporting parents and caregivers of children with disabilities in Bhutan, community engagement emerges as a cornerstone for enhancing well-being. This section highlights the significance of establishing connections within local community, offering avenues for mutual support, resource-sharing, and collective growth.

Why Community Engagement Matters

- **Empowerment Through Unity:** Engaging with the community provides a platform for parents and caregivers to unite, sharing experiences, challenges, and triumphs. Collective strength can empower with a sense of belonging and mutual understanding.
- **Holistic Support Network:** Communities offers resources, knowledge, and expertise. Actively participating provides valuable insights, guidance, and practical solutions to navigate the caregiving journey.
- **Breaking Stigma and Isolation:** Building connections helps dispel myths and misconceptions about disabilities. It promotes inclusivity, reducing feelings of isolation for both caregivers and children, fostering a more accepting and empathetic society.

Example of Community Engagement in Action

- Imagine organizing a community picnic for families with children with disabilities. This event could include inclusive games, activities, and discussions where caregivers share insights on managing daily challenges. Such a gathering nurtures connections, raises awareness about disabilities, and fosters belonging.
- Imagine spearheading a neighborhood gardening project specifically designed to engage children with disabilities. This project aims to create an accessible and sensory-rich garden where children can explore, learn, and interact with nature.
- Imagine initiating a monthly “Caregiver Support Circle” within your community, aimed at fostering a strong support network for parents and caregivers of children with disabilities.
- Engage in campus cleaning activities.
- Develop and maintain play-gardens within the community.
- Organize sports such as football and table tennis, both indoors and outdoors. Additionally, offer culinary training programs and create opportunities for the community to come together and celebrate various occasions and events.



- *“There is no power for change greater than a community discovering what it cares about” Anonymous*

Chapter 10: Inspiring Journeys of Resilience

Triumphing Against All Odds: Bikash's Inspiring Journey

At just six months old, Bikash Mishra faced a severe health crisis when he developed meningitis, which resulted in significant brain damage. Despite doctors initially offering grim predictions, Bikash's parents were determined to save him.

After a journey to Kolkata, where his parents defied the odds and skepticism, Bikash underwent treatment to drain the excess fluid in his brain. Over the years, he endured extensive medical interventions, including medication for brain and physical issues, as well as multiple surgeries to correct leg deformities.

Throughout this challenging journey, Bikash displayed remarkable resilience. He dedicated years to various therapies, such as music therapy and physiotherapy, while also coping with a diagnosis of ADHD and various physical challenges. Nevertheless, he persevered and underwent surgeries to enhance his mobility.

Today, Bikash has achieved remarkable independence and leads a fulfilling life. He takes pleasure in playing piano, singing, and participating in sports such as badminton, table tennis, football, and basketball. He actively contributes to household chores, enjoys socializing with friends, and shares his sense of humor through jokes on messaging platforms and Facebook. Bikash takes immense pride in his identity and radiates confidence in his triumphant journey over adversity.

Tashi's Journey: Overcoming Deafness with Determination

Tashi was born into a humble family of farmers in Bhutan. His parents faced financial constraints and couldn't afford to send him to a special school for Deaf children. Nevertheless, their unwavering determination led them to enroll Tashi in a regular school.

Initially, Tashi encountered difficulties in communication and learning, but his exceptional work ethic shone through. He tirelessly caught up with his classmates, displaying remarkable dedication. Tashi's hard work paid off when he graduated from high school with honors. His thirst for knowledge propelled him to university, where he studied business.

After completing his education, Tashi ventured into entrepreneurship, starting his own business, specializing in handicrafts. Over time, his business flourished, providing employment opportunities for several individuals with disabilities.

Ugyen's Vision: Inspiring Brilliance through Blindness

Ugyen's parents, both educators, recognized her potential early on. They enrolled her in a school for visually impaired children, where her talents blossomed. Fluent in Braille and adept with screen-reading technology, Ugyen's academic achievements soared. Beyond academics, she displayed remarkable musical talent, enchanting audiences with her piano performances.

Currently, Ugyen is a university student in Bhutan, pursuing her dream of becoming a teacher. Her goal is to use her education to empower other visually impaired children to reach their full potential. She actively engages with the visually impaired community, working diligently to increase awareness of the unique challenges faced by visually impaired individuals. Ugyen's story has become a beacon of hope and inspiration for many, proving that determination and talent can transcend adversity.

Passang's Progress: Triumphant over Autism

Passang's parents faced the unfamiliar territory of autism when their son was diagnosed. Despite their initial confusion and fear, their unwavering determination led them to enroll Passang in a school with SEN (Special Education Need) program. Through dedicated effort, Passang made significant strides in communication and daily life skills.

Today, Passang is making strides towards living independently and achieving gainful employment.

Pem's Persistence: Conquering Polio with Resilience

Pem's parents' financial means allowed them to provide her with the best medical care after she was diagnosed with polio. She underwent numerous surgeries and, with the help of a cane, learned to walk again. Pem's parents were unwavering in their support, encouraging her to participate in various activities, including tennis, basketball, and even joining the school's track team.

Today, Pem is a successful businesswoman, owning a thriving shop specializing in handmade souvenirs.

Karma's Artistic Triumph: Thriving with Down Syndrome

Born into a middle-class family, Karma's parents initially worried about his future with Down syndrome. Nevertheless, they were determined to provide him with the best possible care and enrolled him in a school with SEN (Special Education Need) program. Karma excelled at the school, learning to speak, read, and write. He also discovered his passion for art, showcasing his talent through vibrant paintings.

Today, Karma is a flourishing student at a specialized school in Bhutan, making strides towards independence and future employment. Karma's story is an inspiring testament to the potential within every individual, regardless of their circumstances.

Disclaimer:

The stories shared in this chapter are based on real-life experiences of individuals with disabilities in Bhutan, shared with the permission of the parents or guardians of the individuals featured. We are deeply grateful to them for allowing us to share their inspiring journeys as a source of hope and encouragement to others. The names of the individuals may have been altered to protect their privacy. These narratives are intended to inspire and raise awareness about the challenges and triumphs faced by people with disabilities and their families.

Reflections from Parents / Caregivers –

“As a teacher of children with disabilities, I’ve discovered a deep passion, love, and care for teaching this special population.” - Chajay Rinzin (ABS)

“Parenting a child with a disability is a unique journey filled with new knowledge and occasional challenges. However, I also count myself fortunate for the experience.” - Dechen Pem, a Parent

“I embrace being a parent of a child with a disability because every family faces unique circumstances, regardless of disability.” - Passang Sherpa, a Parent

“As a caregiver to my sister with a disability, I focus on providing positive support, even when faced with negativity from others. This helps boost her confidence and resilience in society.” - Sonam Zangmo, a Parent

“Don’t hesitate to reach out to friends, family, and support groups. Connecting with those who understand your situation can be incredibly helpful. ‘Me time’ is also essential.” - Tandin Wangmo, Phensem

“Parents and caregivers face challenges due to societal discrimination and stigmatization when dealing with children with disabilities (CWDs) and persons with disabilities (PWDs). Each individual is unique, and disability is perceived differently by each person. Living with a disability may be challenging, but it is absolutely worth living.” - Suman Pradhan, RENEW (Senior Counsellor)

“When I reflect on my journey as a parent of a child with a disability, I appreciate the minor improvements my child makes. I focus on their strengths and minimize stress over their weaknesses.” - Penden, a Parent

“I consider myself fortunate to be a parent of a child with a disability. It is said that they absorb the family’s bad luck and suffer on our behalf.” - Rinchen Khandu, a Parent

“As a parent and service provider, I find myself growing stronger with each passing day. I feel fortunate to have the opportunity to serve persons with disabilities (PWDs).” - Ngawang Choden, Bhutan Stroke Foundation

“As a caregiver, it’s important to accept ourselves and view it as an individual opportunity to overcome challenges, rather than focusing on the negative barriers faced by our children with disabilities.” - Dorji Phuntsho, IT Officer, DPOB

“Having a child with special needs has made me a better person. It’s taught me positive thinking, patience, compassion, increased happiness, and the belief in success. I’ve also learned

not to take things for granted.” - Lhakpa Dem. a Parent

“Emphasize your unconditional love and commitment to your child. This reflection is a heart-felt and personal exercise, allowing you to express your feelings and experiences as a parent of a child with a disability.” - Dema Choden, a Parent

“As a mother of a boy with multiple disabilities, I sometimes feel overwhelmed and that life is unfair. However, I also focus on the positives and feel grateful for having found a purpose in life. Starting a support group for parents has given my life a meaning.” - Prashanti Pradhan, ED & Co-Founder of Phensem

Resource Mapping

In this section, we outline various organizations and their services that play a crucial role in supporting individuals with disabilities and their parents & caregivers in Bhutan. These organizations offer a wide range of services, including counseling, education, advocacy, and more. Here are the details of these organizations:

ABS (Ability Bhutan Society):	
Website:	www.absbhutan.org
Email:	info@absbhutan.org or ed3abs@gmail.com
Mobile:	+975-1712 8798
Phone:	+975-02-340 747
Address:	Upper Motithang Thimphu: Bhutan
P.O. Box:	1715

Purpose

Ability Bhutan Society (ABS) is a public benefit organization founded on the recognition that persons living with moderate to severe disabilities, primarily children, including their families have special needs. Accordingly, ABS provides direct and early childhood interventions, focused on enhancing the quality life of children with disabilities (CWDs). Advocating and creating awareness on the rights of the child and protection of persons living with diverse abilities in Bhutanese Society. Further, it is also committed to train and develop its human resources, especially the social workers, parents and care givers, as direct service providers to its beneficiaries, primarily the children with special needs.

Currently, ABS offers the capacity building sessions to the parents and caregivers on the last Fridays of each month, covering topics such as yoga, disaster prevention, and comprehensive sexuality education for children, among others. ABS also provide equal opportunities to the parents/ & caregivers to avail training and workshops, both within and outside Bhutan, based on relevance. Such programs are open to all interested individuals. In addition,

- ABS hosts a Community Engagement Summer Program for the children and parents/ caregivers on annual basis, perform the Annual Rimdro together.
- They are part of our routine events, such as observance of the International Disability Days.
- Under aegis of *HOPE 108*, ABS sponsors the livelihood of the children with

- disabilities and their parents, with poor economic background.
- ABS offers free transportation services for parents and children on daily basis.
- ABS provides referral services to various organizations, including hospitals, RENEW, NCWC (National Commission for Women and Children), RBP (Royal Bhutan Police), DPO (Disability People’s Organization), PhenSem, and the Pema Secretariat.
- ABS has been continuously working towards formation of self-help groups (SHGs) within the community at various regions to promote independence among the group members.
- ABS offers business startup funds or seed money for the community-based income generation projects, with funds disbursed through community leaders to support the economic empowerment and the local initiatives.

Draktsho Vocational Training Centre for Special Children & Youth	
Website:	www.draktsho-bhutan.org.
Email:	dekzang@hotmail.com.
Mobile:	+975-77273144.
Phone:	+975-02-327 650.
Address:	Opposite Pension Colony or above Shoppers Store, Thimphu.
P.O. Box:	747.

Purpose

To ensure youth with disabilities in Bhutan are provided with equal opportunities to develop life-skills, aimed towards a self-reliance, by overcoming barriers created by gender or vulnerabilities.

- **Empowerment and Counseling:** emphasizes both empowerment and counseling services.
- **Outreach Program:** conducts home visits to identify the specific needs of individuals with disabilities.
- **Advocacy:** engages in grassroots-level advocacy efforts across all dzongkhags, collaborating with parents and local leaders to support the individuals with living disabilities within our community.
- **Employment Opportunities:** promotes home-based employment options, including activities such as doll making and tailoring.
- **Capacity Building:** provides leadership training to empower individuals with disabilities.
- **Facilitation:** offers support to parents and caregivers, helping them access necessary referral services.
- **Parent Advocacy:** encourages parents to become advocates for their children with disabilities.
- **Entrepreneurship Skills Training:** equips individuals with disabilities with the skills needed to start businesses for sustainable income generation.
- **Vocational Training:** offers selected vocational skills training programs to enhance employment opportunities for individuals with disabilities.

Disabled People's Organization of Bhutan (DPOB)	
Website:	www.dpobhutan.org
Email:	info@dpobhutan.org
Mobile:	+975-1789 9209
Phone:	+975-02-339 996
Address:	JD House, Thori Lam, Changangkha, Thimphu
P.O. Box:	1531

Purpose

Function as a platform to represent all persons with disabilities in policy formulation, legislations, plans and programs that impact the lives of persons with disabilities (PWDs).

- Serves as an umbrella organization, functioning as a bridge between the government and individuals or the community living with disabilities.
- Irrespective of the school grade level, DPO offers educational support to children with disabilities, subject to specific conditions.
- Conducts Disability Equality Training (DET), targeting specific groups to raise awareness about disabilities.
- Provides orientation and mobility skill training.
- Represents the diversity of disabilities, ensuring that parents are included in various aspects of policy and decision-making processes in Bhutan. Thereby acts as a bridge between beneficiaries and policymakers.

PhenSem Parent's Support Group:	
Website:	www.phensem.org
Email Address:	phensemgsb@gmail.com
Mobile No:	+975 77382366
Address:	G P VILLA Flat No. 01, Drodren Lam, Kawang Damisa, Lower Motithang, Thimphu
P.O. Box:	1399

Purpose

Equip and empower parents and families to become better advocates for their children and persons with disabilities to ensure positive changes and quality lives of both children and persons with disabilities, their parents and families. Identify and address gaps in the transition through their life-cycles, which are not covered by other agencies. It ensures smooth transition and progression in their lives and make them, to the extent possible, active members in the society. Create a common platform for parents where the parents and family members could raise their concerns and issues to one single entity to voice and lobby with relevant agencies for solution and action.

- PhenSem operates a drop-in center for parents every Wednesday afternoon, providing mentoring and peer counseling. They also offer calling facilities for assistance.

- The center offers self-care activities to support the well-being of parents.
- Parent empowerment programs are conducted to enhance parenting skills and knowledge.
- Skill sharing and networking opportunities are made available to help parents connect and learn from each other.
- PhenSem focuses on positive future planning for families.
- They facilitate inclusion in schools and Early Childhood Care and Development Centers (ECCDs) through parent-teacher partnerships.
- PhenSem supports the development of parent advocates through in-house capacity building programs.
- They provide a family resource center to assist families in accessing necessary resources.
- PhenSem has chapters in Paro, Gelephu, and Phuentsholing, extending their services to different regions.
- The organization operates Assistive Technology (AT) facilitation centers to enhance accessibility and support for individuals with disabilities.

Bhutan Stroke Foundation (BSF):	
Website:	www.bhutanstrokefoundation.org
Email:	info.bhutanstrokefoundation@gmail.com
Mobile:	+975 17625956
Phone:	+975 02351160
Toll Free No:	1321321
Address:	Dorj's House, above The Pema's, Lower Motithang, Thimphu
P.O. Box:	1101

Purpose

Facilitate individuals suffering from or at risk of stroke, to access services from the health facilities Advocate and facilitate awareness programs with relevant Govt. agencies on risk and prevention of stroke. Facilitate non-medical and community-based rehabilitation services to the patients diagnosed with stroke in holistic manners and carry out research on stroke related issues.

- Foundation offers online physiotherapy services.
- Meditation sessions are held every Friday, available both online and offline.
- The foundation has access to Fablab facilities for designing custom physiotherapy equipment.
- A range of physiotherapy equipment is available, generously donated by JICA (Japan International Cooperation Agency), based in Thimphu.
- The foundation provides referral services to hospitals for individuals in need.
- They offer a life engagement program that includes activities like cooking, cleaning, and more.
- The Foundation conducts Stroke Risk Assessment to evaluate the risk of stroke for the general public at various occasions & public gatherings.

Respect, Educate, Nurture, and Empower Women (RENEW):	
Website:	https://renew.org.bt/
Email:	info@renew.org.bt
Mobile:	+975 17126353
Phone:	+975 02332159
Address:	Phenday Oudphel Lam, Phendey Gyatshel, Lower Motithang, Bhutan
P.O. Box:	1404

Purpose

To forge a better understanding of gender inequalities at all levels of society. To provide support and care services for victims of violence and offer them opportunities to continue their lives as independent socially and economically members of society. To ensure a safe environment for the marginalized people through strategic planning and implementation of activities. To assure future sustainability of the RENEW organization.

- RENEW operates 24/7 and their helpline number is 17126353.
- They offer counseling services for individuals, couples, and families, catering not only to women but also to individuals with disabilities, mental illness, HIV, and (LGBTQI+) individuals.
- Legal services are available to provide support and guidance.
- RENEW provides livelihood skills training in tailoring, weaving, flowering, and mushroom cultivation.
- Health support is available through the Health Assistant (HA) at Gawaling Happy Home (GHH), where survivors receive care and support within the community.
- Members of GHH undergo training and counseling.
- Residential counselors are present at GHH to provide ongoing support.
- RENEW operates in 7 community centers in Paro, Samtse, Phuentsholing, Gelephu, Punakha, Bumthang, and Tsirang.
- A Community-Based Support System (CBSS) is in place with volunteers in all 20 dzongkhags.
- RENEW offers microfinance services with a loan amount of 2 lakhs for groups of 4 members.
- Special training is provided to women survivors to enable them to successfully run their businesses.

PEMA Secretariat:	
Website:	www.thepema.gov.bt
Email:	enquiry@thepema.gov.bt
Phone:	+975 02 332862
	<ul style="list-style-type: none"> • Call 1010 or 112 for The PEMA Helpline Services • 1098 for the Protection Services
Address:	Dharshing, 136 Jiji Lam, opposite Bhutan Table Tennis Federation, Thimphu
P.O. Box:	150

The PEMA Secretariat is responsible for spearheading the country’s national response to mental health. It was established in 2021 under the Royal Command of Her Majesty, The Gyaltsuen, and its mission is to build a society that promotes the well-being of all Bhutanese, supported by enabling mental health policies and programs, transformative multi-sectoral partnerships, and a proactive service delivery network.

The PEMA Secretariat has three core divisions:

- Prevention and Engagement Division
- Response Service Division
- Restorative and Rehabilitation Division

Ministry of Education and Skills Development	
Website:	http://www.education.gov.bt/
Toll Free No:	9900
Address:	Ministry of Education and Skills Development (MoESD), Kawajangsa,
PO Box:	112, Thimphu
Vision:	An educated and enlightened society of GNH, built and sustained on the unique Bhutanese values of the dam-tsig ley gju-drey.
P.O. Box:	112

Ministry of Health	
Website:	https://www.moh.gov.bt/
Phone:	+975-2-328095, 321842, 322602, 328091
Address:	Kawajangsa, Thimphu
Vision:	A nation with the best health.

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- Bhutan Building Resolutions 2018.
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