BLACK CAREGIVER
ESSENTIALS

by Sawubona Africentric Circle of Support

africentric circle of support
SAWUBONA

Empower

Educate

Enlighten

CANADIAN RED CROSS
CROIX-ROUGE CANADIENNE

Credits

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Thank You

We want to express our immense and heartfelt appreciation to The Canadian Red Cross Community Services Recovery Fund Program (CSRF) for the funding of this project to enable Sawubona Africentric Circle of Support to produce this much-needed Handbook. Their financial support was not just a contribution but a catalyst, and played a crucial role in creating this essential asset for Black caregivers.

We are also grateful for the voices of the many Black Caregivers whose experiences of raising and caring for a family member or loved one with a disability have been captured in this Handbook. Thank you for sharing your stories that will be for the benefit of the wider community and its allies.

FOREWORD

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Why "Black Caregivers Essentials"?

When my son was first diagnosed with autism, at the age of 4, my world went spinning. Even prior to receiving the official diagnosis, I explored the World Wide Web, as I referred to it then, to learn more as my mommy senses told me that something just wasn't right. At the time, in 2000, the projected outcomes for my son were not good. Institutionalization, unemployment, no hope for any type of independence. This was the messaging coming at me like a speeding truck. My son was the first in my family, on both sides, to be living with a developmental disability.

As I continued to read, and as I attended parent groups, seminars, even advocacy events, I felt invisible, alone, an anomaly. You see, I identify as a Black woman. My son, now a Black man. Yet in all of the circles that I was in, the articles I read and the visuals that accompanied them, I saw no one that looked like me or my son… although I did see them in my son's classroom and at his various programs. So what chance did my son have to be included and valued if the messaging seemed to communicate that people like him don't exist? And if you don't exist, do you matter?

As I met other Black caregivers, along my journey, we realized that it was time to create a group that would affirm our existence and value, and the hopes and dreams that we have for our loved one living with a disability. This is how Sawubona Africentric Circle of Support was born.

In this resource what you will find:

- Questions that you may have thought about but didn't have the courage to ask and answers to some of those questions.
- Affirmation of some of those "big feelings" you have had but didn't feel justified to feel.
- Some homework to open your mind and heart to "what might be" and inspiration to healing, first for yourself, so that you can be better for your loved one.

I am grateful to the families that shared their stories and to Esther Guzha and Khyara Scott who captured them so well. Thank you Khyara for the research to help provide some context to this work and for laying it out in an easy to read format.

Thank you Canadian Red Cross for the funding to create this resource that we know will support caregivers, families, allies and agencies intentional about disrupting systemic racism, ableism and anti-Black racism and acknowledging the harm that it has caused and continues to cause in the lives of too many.

This resource is meant to be shared and used as a tool for Black families to successfully run this race.

Sherron Grant
Executive Director and Co-Founder
Sawubona Africentric Circle of Support

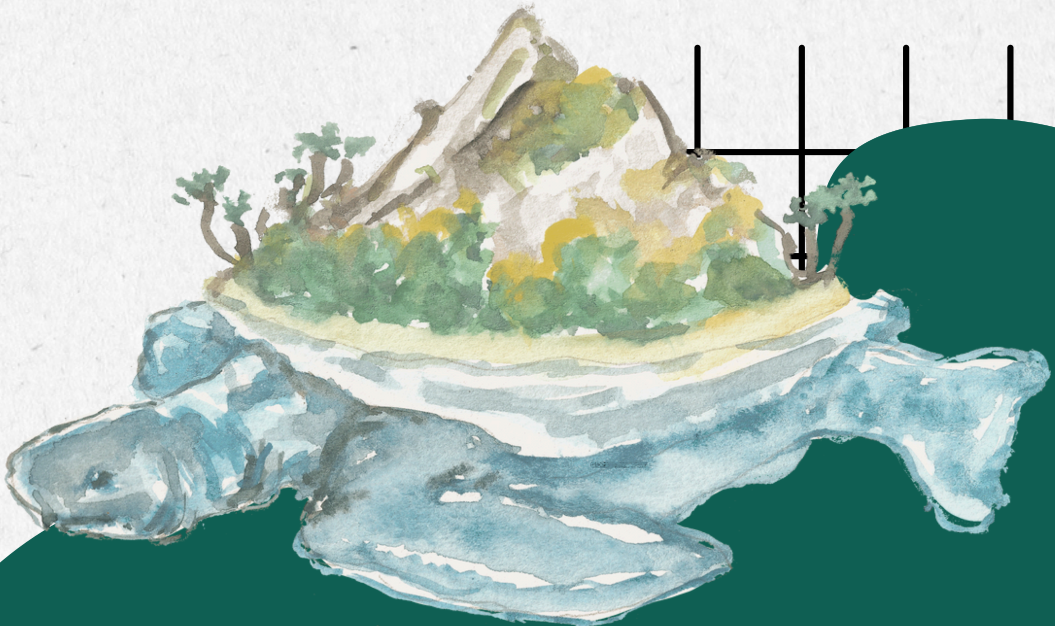
Sherron Grant

Sawubona Africentric Circle of Support (Sawubona) was created to serve Black families across Canada. This parent/caregiver handbook is geared towards Black families and caregivers in Ontario, but the information and principles can be applied in any community where there are Black parents/caregivers and the individuals they support.

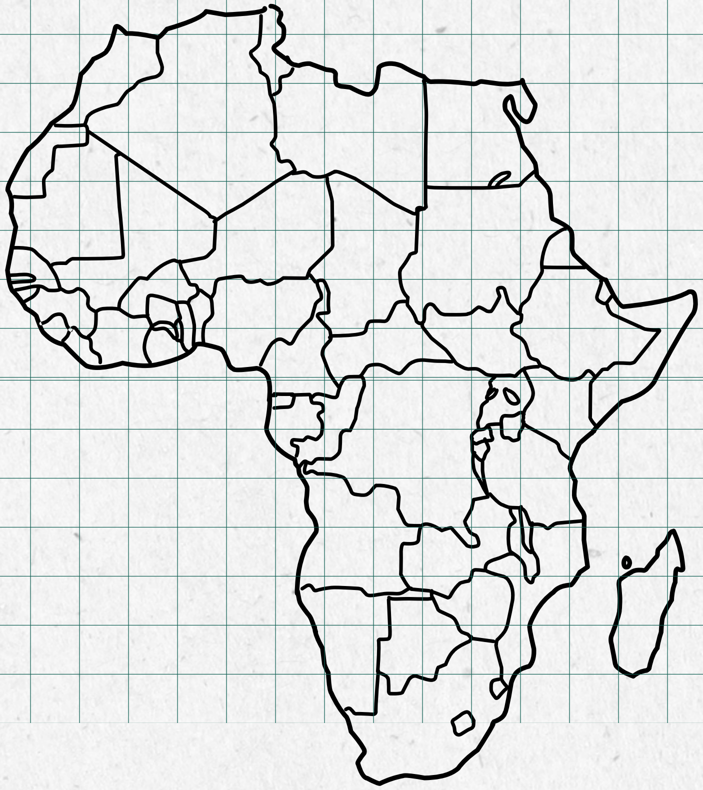
LAND ACKNOWLEDGEMENT

With our head office based in the Greater Toronto Area, we acknowledge the land we are working on is the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples and is now home to many diverse First Nations, Inuit and Métis peoples. We also acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit.

All people living in Canada are treaty people; we are all part of a relationship based on respect, co-operation, partnership and recognition of Indigenous rights.



AFRICAN ANCESTRAL ACKNOWLEDGEMENT



We continue to observe a moment to honour those who resisted and were left at the bottom of the Atlantic Ocean; those who resisted on the plantation and fought for our freedom from the shackles of enslavement; and those who fought to emancipate from the shackles of colonial rule and gain our countries' independence.

We honour those who have led lives of service and stood up for social, political and economic justice, and those who have confronted and dismantled oppressive practices, challenged institutions and have built affirming and equitable examples to inspire us all. It was you all, our ancestors, who have sacrificed so that we may be here.

You, our ancestors, stood up against dehumanization, economic exploitation, gender discrimination and violence, religious bigotry and other oppressive forces. It was you, our ancestors, who fearlessly confronted and denounced one of the worst forms of oppression the world has ever known: anti-Black/African racism. We consciously stand on your sturdy and courageous shoulders and for that, we thank you.

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MISSION & VISION

Sawubona Africentric Circle of Support is an incorporated non-profit organization that aims to **EMPOWER** Black caregivers of individuals with disabilities and their families to use their voice and create change.

We **EDUCATE** families on services, resources and expertise available to them and their family members. We educate systems to better connect with Black families through decolonized and better informed practices of support to Black families and their systems of support. We **ENLIGHTEN** as we build a strong community of support for Black families to remain hopeful for the future for their loved one.

Mission

The **MISSION** of Sawubona Africentric Circle of Support is to cultivate and improve the self efficacy of Black caregivers of persons with a disability and their families by providing necessary resources and support.

Vision

Sawubona's **VISION** is for every Black caregiver of a family member with a disability to feel a sense of belonging.

OUR VALUES

1 Partnership

We are stronger together.

2 Cultural Safety

We build relationships through trust, respect and honesty.

3 Optimism

We believe a better future is possible.

How To
USE THIS HANDBOOK

Using the Black Caregiver Essentials

Caregiving is an important responsibility, whether it be for your child or your family member with a disability. It can be exciting at times and, as we know, can come with its share of challenges. The Black Caregivers' Essentials Handbook - a project of Sawubona Africentric Circle of Support is an easy to follow guide that provides Black caregivers with critical information for the caregiving journey, with unique cultural perspectives. You can use it any way that suits your particular circumstances. It is meant as a resource meaning you don't have to read it as you would a novel from one chapter to the next.

Individually, you can use the Table of Contents to jump straight to your desired topic. **Groups of families/caregivers** can come together, using the Handbook as a discussion guide, similar to a book club. By reviewing relevant sections of the resource, you can foster a sense of community and stimulate meaningful discussions, enhancing your collective caregiving knowledge. In addition, sharing the information learned with other folks in the community, like places of worship and community gatherings helps more people and helps reduce the stigma around disabilities.

For Agencies and Researchers, the Handbook can be a resource to provide insights on how to best support Black families to help reduce stigma and the impact of racism in their caregiving journeys.

REFLECT

The light bulb symbol in the handbook highlights sections where you can reflect on the questions provided. These questions are designed to help you think deeply about your caregiving experience and gain insights, making your journey more manageable and meaningful.

RESPOND

The pencil symbol indicates sections where you're invited to write or type your answers to the provided questions. By doing so, you can discover actionable steps to improve your caregiving experience, as your responses help clarify your thoughts and reveal practical solutions.

DEMYSTIFYING DISABILITY

Disability often remains misunderstood due to societal misconceptions, stereotypes, and lack of awareness. As caregivers, it's crucial to recognize that education about disability is an ongoing journey. This commitment entails understanding the diverse experiences and needs of individuals with disabilities. However, navigating these complexities becomes even more challenging when considering intersections with race, particularly within Black communities.

Addressing these identity intersections is essential because each person's experiences are unique, and everyone deserves to be understood and supported appropriately. By actively seeking knowledge, acknowledging these intersections, and fostering empathy and understanding, caregivers can better support individuals with disabilities, creating more inclusive and equitable environments for all.

CORE UNDERSTANDINGS ON DISABILITY

Understanding disability isn't a straightforward concept; it's like a puzzle with many pieces. Some might see it as a journey that changes over time, both physically and emotionally. Others view it not just as a label, but as something that brings unique challenges in how we function day-to-day. Think about it: everyone has things they struggle with, right? But for some, those struggles come with a label. It's like saying, "Hey, we're all in this together, but some of us wear our challenges on our sleeves." It's all about seeing disability from different angles, understanding that it's not just one thing, but a mix of experiences, perceptions, and abilities

1
Types of Disabilities

2
Language

3
Stigma & Accessibility

4
Call to Action

Take a moment to think through each piece of the puzzle. What are your thoughts and assumptions about each subject in relation to disability? Keep these thoughts in mind as you read the next few pages.

1

Types of Disabilities

Understanding disability is a constantly evolving journey filled with complexities. While we try to organize disabilities into broad categories, these classifications only give us a glimpse of the diverse experiences within the disability spectrum. Our understanding grows as we uncover new insights, challenge old beliefs, and advocate for inclusivity. It's important to recognize that each person's experience of disability is unique.

While these categories help us understand, they should be approached with flexibility and an understanding of the many intersections within the disability community. Embracing this complexity leads to a more inclusive and fair approach to addressing disability, respecting the diversity and autonomy of every individual.

Visible VS Invisible

Apparent/visible disability: Noticeable to others through outward appearance or communication, such as using a wheelchair or having a prosthetic limb.

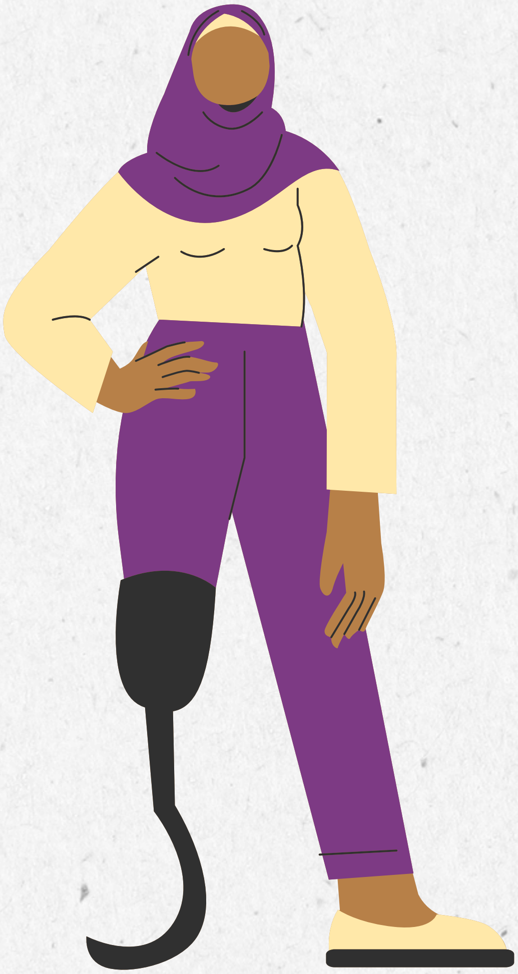
Non-apparent/invisible disability: Not immediately noticeable when interacting with someone. The same disability may sometimes be apparent and other times invisible, like a learning disability or autism.

Can you think of a few scenarios where having an understanding of apparent/visible and non-apparent/invisible disabilities are important?

Example:

Accessible seating on public transportation. Be careful who you assume should and shouldn't be sitting there.

BROAD CATEGORIES OF DISABILITY



Chronic illnesses

A chronic illness can persist and affect different parts of a person's physical and mental health over an extended period of time.

e.g. Asthma, Type 2 Diabetes

Communication disorders

When someone has a communication disorder, it can impact how they share or understand information.

e.g. Stuttering

Developmental disabilities

A developmental disability may alter a person's physical or cognitive growth outcomes.

e.g. Down Syndrome

Hearing disabilities

Hearing disabilities can affect how well someone hears, whether it's partially or completely. This may impact speech.

Learning disabilities

Learning disabilities impact how individuals learn, process information, and comprehend various subjects, influencing their educational experiences and requiring tailored approaches to support their learning needs.

e.g. Dyslexia, Attention Deficit Hyperactivity Disorder (ADHD)

Mental health disorders

Mental health disabilities have the potential to impact various aspects of an individual's psychological well-being, including their thoughts, emotions, and behaviours. This may influence their overall mental and emotional functioning .

e.g. Eating Disorders, Depression

Neurological disorders

Neurological disorders affect the nervous system, from the brain to peripheral nerves, impacting physical, cognitive, and emotional functions, requiring tailored care for management and support.

e.g. Seizure Disorders , Autism

Physical disabilities

A Physical disability can impact a person's movement, dexterity, or stamina. This may cause a need for supports for accessibility.

e.g. Amputations/loss of limbs, Arthritis

Vision disabilities

Vision disabilities impair a person's ability to see, either partially or completely.

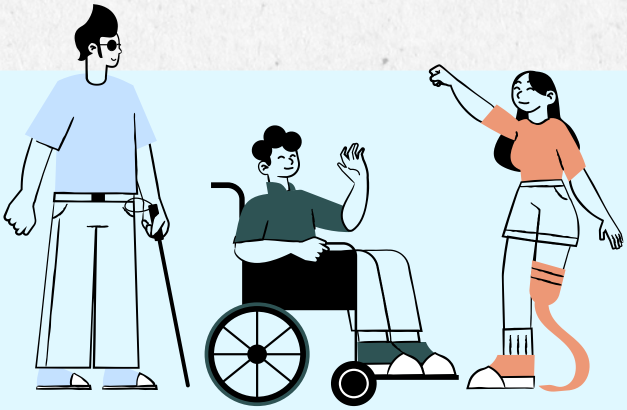
Intellectual disabilities

Intellectual disabilities encompass conditions that may impair a person's communication, cognition, and personal and interpersonal activities.

e.g. Fragile X Syndrome, Fetal Alcohol Spectrum Disorder (FASD)

Remember disability categories, like those mentioned, encompass a wide range of experiences. Continual learning and exploration are crucial to understanding the nuances within each category. An individuals' experiences may not neatly fit into predefined labels.

What are 3 ways you can learn more about disability?



2

Language

Person-first Language (PFL): Person-first language in disability emphasizes the individual before the disability. For example, "person with a disability." This approach highlights the person’s identity and humanity rather than defining them solely by their disability.

Identity-first Language (IFL) : Identity-first language acknowledges disability as an integral part of a person's identity, connecting them to a community, culture, and history. For example, saying “I am autistic” emphasizes that the disability is a core aspect of who they are, fostering a sense of belonging and shared experience.

A note on tone:

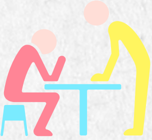
The tone you use to speak about disability is crucial because it conveys your attitude towards the subject. Since much of communication is non-verbal, tone, along with body language and facial expressions, plays a significant role in ensuring that the message is received as intended.

Being mindful of how you speak about disability is crucial because language shapes perceptions and influences attitudes. Words can either empower or stigmatize individuals with disabilities. Using respectful and inclusive language fosters a sense of dignity and belonging, while derogatory terms or insensitive remarks can perpetuate stereotypes and discrimination.

Different ways we communicate

Verbal communication

Verbal communication includes speaking face-to-face, by phone, or online. It’s about word choice, message structure, intonation, and non-verbal cues when in person.



Non-Verbal communication

Facial expressions, posture, and eye contact, often conveys more than words. Non-verbal cues might reveal discomfort or bias despite verbally supporting accessibility initiatives for disability inclusion.

Written communication

Written communication involves conveying messages through written words, including letters, emails, reports, and texts, to share information clearly.

Visual communication

Our online digital media posts convey messages, like travel or achievements, and often aim to evoke emotions, like sympathy or joy.

In what way do you speak about disability? What are some of the reasons you speak about disability in the way that you do?

3

Stigma & Accessibility

Intersectional thinking is crucial in understanding the multifaceted experiences of individuals with disabilities, particularly within the context of race and ethnicity. This approach recognizes that individuals may experience compounding forms of discrimination and marginalization based on the various aspects of their identity.

When considering disability within Black communities, it's essential to acknowledge how stigma and accessibility issues intersect, leading to unique challenges. Black disabled individuals often encounter multiple layers of discrimination, making it harder to access resources and support systems.

Examples of barriers in everyday life

LIMITED ACCESS TO HEALTHCARE DUE TO RACIAL BIASES AND ECONOMIC DISPARITIES.

DISCRIMINATION IN EMPLOYMENT OPPORTUNITIES, LEADING TO HIGHER RATES OF UNEMPLOYMENT OR UNDEREMPLOYMENT.

INADEQUATE REPRESENTATION IN MEDIA AND PUBLIC DISCOURSE, PERPETUATING STEREOTYPES AND ERASING DIVERSE EXPERIENCES.

ACCESSIBILITY BARRIERS IN PUBLIC SPACES AND TRANSPORTATION, EXACERBATING SOCIAL EXCLUSION AND ISOLATION.

Caregivers who are able-bodied also face stigma and accessibility challenges in their day-to-day lives.

Being judged or questioned for using accessible parking spaces when accompanying a disabled individual.

Feeling overlooked or dismissed by medical professionals when advocating for a disabled loved one's needs.

Experiencing discomfort or anxiety when navigating inaccessible environments while providing care.

Facing societal expectations of "normalcy" and feeling pressure to hide or downplay caregiving responsibilities in professional or social settings.

When Blackness & Disability Intersect

Adding disability identity to Blackness exacerbates stigma by compounding negative stereotypes and reinforcing existing biases. This intersectional discrimination can have profound effects on various aspects of life, including employment, education, healthcare, and interactions with law enforcement. It highlights the importance of addressing not only racism but also ableism in efforts to promote equity and justice for all marginalized communities.

Have you ever felt stigmatized or judged because of your caregiving role or your association with someone with a disability?

Can you identify any accessibility barriers you've encountered in your community or workplace, and how did they impact you or someone you care for?

2 **Common stereotypes about Black people are the "lazy" stereotype and the "dangerous/criminal" stereotype.**

When disability identity intersects with Blackness, these stereotypes can be exacerbated, leading to increased stigma and discrimination.

The "Lazy" Stereotype

The stereotype of Black people as lazy is rooted in historical prejudices and systemic racism. When a Black person also has a disability, they may face additional assumptions that they are incapable or unwilling to work due to their disability. This compounding stigma can make it even more challenging for Black disabled individuals to access employment opportunities and can contribute to economic hardship and social exclusion.

The "Dangerous/Criminal" Stereotype

Black people are often stereotyped as dangerous or criminal, a perception perpetuated by media portrayals and systemic biases. When disability is added to the equation, Black disabled individuals may face heightened fear and suspicion. They may be perceived as doubly threatening, reinforcing harmful stereotypes and increasing the likelihood of discrimination, harassment, or even violence from law enforcement or community members.

4

Call to Action

Caregivers wield significant influence in shaping perceptions and experiences for individuals with disabilities.

Understanding disability stigma and utilizing tools like inclusive language are essential steps, but their true impact lies in their application. As primary advocates and supporters, caregivers play a pivotal role in shaping societal attitudes and experiences for individuals with disabilities. By actively applying and spreading this knowledge, caregivers can foster environments of acceptance and inclusion.

Here are some questions to keep in mind for your ongoing learning.
Stay open and honest. This is an opportunity for growth; it's okay to not know something. It's in sharing these knowledge gaps that previously unaddressed issues can be addressed

1. How can I actively incorporate person-first language and challenge ableist language in my daily interactions?"
2. What accessibility barriers exist in my community, and how can I advocate for their removal?
3. What opportunities do I have to educate others about disability stigma and promote inclusion?
4. How can I support legislative initiatives that advance disability rights and accessibility?
5. Am I regularly examining my own beliefs and biases about disability to ensure they align with principles of inclusivity and respect?
6. In what ways can I amplify the voices and perspectives of individuals with disabilities in conversations and decision-making processes?
7. How can I ensure that the environments and activities I facilitate are accessible and inclusive for individuals with disabilities?
8. What resources and support networks can I connect individuals with disabilities to in order to enhance their well-being and empowerment?
9. Am I actively seeking out opportunities to learn more about the diverse experiences and needs of individuals with disabilities?
10. How can I challenge societal attitudes and structures that perpetuate discrimination and exclusion against individuals with disabilities?


LEAD
WITH
JOY

SELF CHECK IN

Self-care is vital for Black caregivers as the emotional demands of caregiving can be overwhelming. Providing care often entails a rollercoaster of emotions, and there are moments when the caregiver themself may need support. It's crucial to acknowledge and address these emotions before reaching burnout. By unpacking these feelings and exploring ways to help oneself, caregivers can cultivate resilience and maintain their well-being.

Remembering that taking care of oneself enables them to better show up for others and reinforces the importance of self-care. Prioritizing self-care isn't selfish; it's a necessary step towards sustaining the caregiving journey while preserving one's own mental, emotional, and physical health.

WHERE YOU ARE AT

We see the weight you're carrying on your shoulders. The journey you're on is filled with challenges and uncertainties, and it's okay to feel overwhelmed.

Caring for someone you love can stir up a whirlwind of emotions—from exhaustion to frustration to moments of pure joy—and it's all part of the journey. But through it all, please remember that you're not alone. We're here to walk alongside you.

Take a moment to breathe; to feel all those emotions coursing through you, and know that it's okay to let yourself feel them.

RESOURCE AUDIT

Chances are you aren't starting with nothing. Everything you've learnt in your day to day life as a caregiver has given you knowledge. Take a moment to think of those wins and challenges. Here are a few prompts/ questions to help you get started.

1

ON THE BEST DAYS

Each day can vary as a caregiver. On my best day, where it wasn't easy but I felt well prepared to handle any challenges, what tools or supports did I use to create this reality?

2

ON DIFFICULT DAYS

On a difficult day, where I felt I've reached my limit, what tools and supports were I missing? Why?

3

MY ENVIRONMENT

What impact does my current environment (e.g. my home, community, city) have on the quality of care I can provide ?

4

MY EMOTIONS

If I were to track my emotions throughout any given day, what emotion would come up the most?

UNDERSTANDING THE CAREGIVER'S BURDEN

What is the caregiver's burden ?

Caregiver's burden, often referred to as caregiver stress or caregiver strain, is a term used to describe the physical, emotional, psychological, and financial challenges experienced by individuals who provide care for a loved one who is ill, disabled, elderly, or otherwise dependent on their assistance.

This burden can manifest in various ways and is influenced by the nature of the caregiving role, the health condition of the care recipient, and the resources available to the caregiver. While caregiver burden can affect anyone in a caregiving role, it is often particularly pronounced among family members who provide informal, unpaid care to their loved ones.

SIGNS OF CAREGIVER BURDEN

1 Stigma

Black caregivers often face stigma due to intersecting prejudices about race and caregiving. They may encounter stereotypes, discrimination, and lack of support, which can compound the challenges of caregiving and contribute to feelings of isolation and inadequacy.

2 Role Strain

Caregivers may struggle to balance their caregiving responsibilities with other roles and obligations, such as employment, parenting, and household management. This role strain can create conflicts and tensions within families and impact caregivers' overall well-being.

3 Financial Pressure

Caregiving often requires significant financial resources, including out-of-pocket expenses for medical care, medications, adaptive equipment, home modifications, and professional caregiving services. Caregivers may face financial strain due to reduced income from taking time off work or quitting their jobs to provide full-time care.

4 Uncertainty about the Future

Caregivers often face uncertainty about the progression of their loved one's illness or disability. This makes knowing how long they will need to provide care and considering what will happen if they are no longer able to fulfill their caregiving role more daunting. This uncertainty can cause stress and anxiety.

5 Social Isolation

The demands of caregiving can lead to social isolation as caregivers may have limited time and energy to maintain relationships with friends, family, and community members. Feelings of loneliness and isolation can exacerbate caregiver stress and contribute to mental health issues such as depression and anxiety.

6 Emotional Distress

Providing care for a loved one can evoke a range of emotions, including sadness, grief, frustration, guilt, and anxiety. Caregivers may struggle with feelings of helplessness or inadequacy, especially if they are unable to meet all of their loved one's needs or if the care recipient's condition worsens.

Physical Strain

Caregivers may experience physical exhaustion from assisting with tasks such as bathing, dressing, lifting, and transferring their care recipient. This physical strain can lead to fatigue, muscle pain, injuries, and chronic health problems over time.

Sometimes our mind feels like that

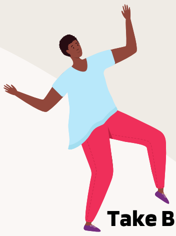
What emotions do you often find yourself tangled in?

SELF CARE STRATEGIES

It's essential to recognize that strength does not negate the need for support or the right to ask for help. In fact, resilience often thrives within a supportive community that acknowledges and addresses the challenges faced by Black caregivers. Care strategies such as practicing self-compassion, setting boundaries, seeking social support, and prioritizing self-care can empower Black caregivers to continue showing up for themselves and those in their care. By fostering a culture of mutual support and understanding, caregivers can honor their own needs while also advocating for the well-being of their communities. Remember, strength lies not only in enduring hardships alone but also in coming together as a collective to uplift and empower one another.

Seek Support Groups

Connect with support groups or online communities specifically for Black caregivers of disabled individuals to share experiences, advice, and encouragement.



Take Breaks

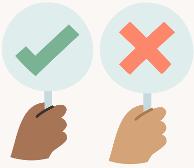
Schedule regular breaks to rest and recharge, even if it's just for a few minutes each day. Delegate caregiving responsibilities when possible to give yourself time to decompress.

Practice Mindfulness

Incorporate mindfulness practices such as deep breathing, meditation, prayer, or yoga into your daily routine to reduce stress and promote emotional well-being.

Prioritize Sleep

Ensure you get enough sleep each night to support your physical and mental health. Establish a bedtime routine and create a comfortable sleep environment to improve sleep quality.



Set Boundaries

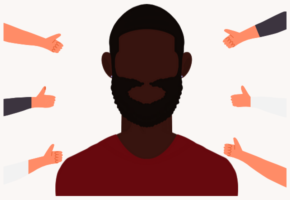
Learn to say no to additional responsibilities or commitments that may overwhelm you. Establish clear boundaries to protect your time and energy.

Engage in Hobbies

Make time for activities you enjoy and that bring you joy and relaxation, whether it's reading, gardening, cooking, or listening to music.

Stay Informed

Educate yourself about your child's or loved one's disability, treatment options, and available resources. Knowledge can empower you to make informed decisions and advocate effectively.



Celebrate Achievements

Take time to celebrate the small victories and achievements, both yours and your loved one's. Recognize and appreciate your resilience and strength in navigating challenges.

Practice Self-Compassion

Be kind to yourself and acknowledge that it's okay to feel overwhelmed or to make mistakes. Treat yourself with the same compassion and understanding that you offer to others.

Seek Professional Help

Don't hesitate to seek professional support from therapists, counselors, or mental health professionals who can provide guidance and assistance in managing stress and emotions.

Remember that self-care is not selfish; it's essential for maintaining your well-being and capacity to provide care for your loved one. Prioritize self-care as an integral part of your caregiving journey.

BARRIERS TO SELF CARE

Self-care is essential for Black caregivers to sustain their health and caregiving abilities. However, they often face significant barriers, including systemic racism, financial pressures, and limited access to supportive services. These challenges can make self-care seem unattainable, yet it remains a vital practice to prevent burnout, reduce stress, and maintain overall well-being. Despite these difficulties, prioritizing self-care is crucial for ensuring that caregivers can continue to provide the best possible care for their loved one while also taking care of their own mental and physical health.

POTENTIAL BARRIERS

1 Guilt

The entanglement of lives between caregiver and care recipient can blur boundaries and intensify feelings of guilt about prioritizing self-care. Caregivers may feel guilty about spending time on themselves, believing they should always prioritize the needs of their loved one above their own. This sense of guilt can hinder caregivers from seeking help or taking time to recharge, ultimately impacting their physical, emotional, and mental well-being.

2 Unpredictability

The unpredictable nature of caregiving adds another layer of complexity. The day-to-day responsibilities of caregiving can be erratic, making it challenging to plan or schedule time for self-care activities. This unpredictability can disrupt personal routines and make it difficult for caregivers to carve out time for themselves amidst their caregiving duties.

3 Work Strain

Work strains also pose significant barriers to self-care for Black caregivers. Balancing caregiving responsibilities with work commitments can be overwhelming, leading to stress, fatigue, and burnout. Many Black caregivers may also face economic challenges, making it difficult to access resources or support services that could alleviate some of the caregiving burden.

4 Challenging Behaviour (CB)

One significant barrier is the presence of challenging behaviors (CB) in the individuals they care for, which can make socializing and finding respite difficult. CB can create isolation, as caregivers may feel hesitant to seek support from friends or participate in social activities due to concerns about how their loved one's behavior might be perceived.

1. What are some things that prevent me from practicing self care?
2. What activities or practices bring me joy and relaxation, and how can I incorporate them into my daily routine, even in small ways?
3. Who in my community or support network can I reach out to for help, encouragement, or a listening ear when I need it?
4. What boundaries can I set to protect my time and energy, and how can I communicate these needs to others effectively?

COLLECTIVE COPING

How have Black caregivers approached seeking help?

Black caregivers face a myriad of unique challenges compounded by societal oppressions and chronic stressors, often with fewer physical resources to aid in coping.
However, Black families have demonstrated resilience and the ability to overcome these obstacles, attributed largely to the strength of their familial networks and cultural values. Coping with these challenges is a dynamic process. The coping strengths of Black families, as outlined in Murry and colleagues' Black Family Stress and Coping (BFSC) model, offer insights into how these caregivers navigate the stressors they encounter.

Do you agree?

As a Black caregiver, do you resonate with the study's findings? How is your experience similar? How does it differ?

1 Seeking social support

Both formal and informal social support networks play a crucial role in helping Black caregivers cope with the demands of caregiving. While formal support from external agencies can provide practical assistance, informal support from family, friends, and other caregivers offers emotional reassurance and understanding.

2 Positive reappraisal

Black caregivers employ positive reframing techniques to find strength and resilience in challenging situations. They view their child's disabilities as opportunities for growth and learning, emphasizing the importance of patience, gratitude, and spiritual practices in coping with stress.

3 Planful problem-solving

Black caregivers frequently engage in active efforts to solve problems related to their child's disability, such as seeking diagnostic testing and accessing resources. They demonstrate resilience and determination in addressing the challenges they face, often partnering with external organizations or utilizing available community resources.

4 Self-care

Despite societal pressures to prioritize their children's needs, Black caregivers recognize the importance of self-care in maintaining their own well-being. They engage in activities such as exercise, creative hobbies, and spiritual practices to recharge and rejuvenate, even amidst the demanding caregiving responsibilities.

5 Optimism

Black caregivers maintain a hopeful outlook, believing that they have the strength and resources to overcome challenges. Their optimistic mindset serves as a protective factor against the detrimental effects of stress, enabling them to navigate adversity with resilience and determination.

6 Kinship support

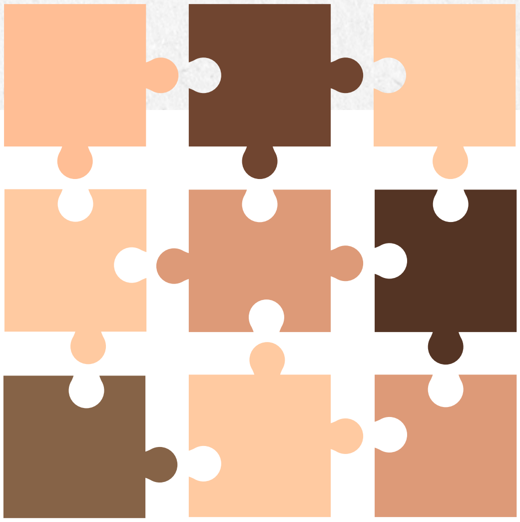
Family ties and support networks within the Black community provide a source of strength and solidarity for caregivers. Kinship support networks offer practical assistance, emotional encouragement, and a sense of belonging, helping caregivers feel supported and understood in their caregiving journey.

7 Faith /spirituality

Spiritual practices and involvement in religious communities provide Black caregivers with a sense of comfort, purpose, and meaning amidst the challenges they face. Faith serves as a source of hope and resilience, guiding caregivers through difficult times and offering solace in moments of distress.

8 Collective socialization

Engaging with other caregivers and community members who share similar experiences fosters a sense of collective identity and solidarity. Collective socialization enables caregivers to exchange advice, support one another, and advocate for their children's needs within their communities, creating inclusive spaces for mutual understanding and empowerment.



A FINAL BIT OF ENCOURAGEMENT

To Black caregivers who may feel undeserving of self-care practices: remember, you are worthy of care and attention, just as much as the loved ones you care for. Despite the barriers such as time constraints, financial strain, and societal stigmas, it is essential to prioritize self-care. Taking care of yourself isn't a luxury—it's a necessity for your well-being and your ability to provide the best care possible for your loved one.

Self-care doesn't have to be grand or costly. It can be as simple as taking a few minutes each day to breathe deeply, enjoying a quiet cup of tea, or taking a short walk. The key is consistency and finding small moments that bring you peace and rejuvenation. Recognize that you deserve time for yourself. Your well-being is integral to the well-being of your family.

By caring for yourself, you are not being selfish; you are ensuring that you can continue to be strong, resilient, and present for those who depend on you. Embrace self-care as a vital part of your life, and know that by doing so, you are setting a powerful example for your children and community. You are worthy of care, love, and moments of joy—never forget that.

BUILDING YOUR VILLAGE

Your circle of support shouldn't adhere to a single template; it should be as diverse as the individuals within it. Each person you encounter, whether family, friends, or professionals, brings a unique set of qualities and perspectives that can contribute in various ways to your loved one’s well-being. From the empathetic friend who lends a listening ear to the knowledgeable therapist who offers specialized guidance, every member has something valuable to offer.

Instead of focusing solely on specific roles or relationships, prioritize fostering values such as empathy, reliability, and compassion in the people around you. By nurturing these qualities in your support network, you create a dynamic and inclusive environment where everyone's strengths can shine, ultimately enriching the lives of both you and your child.

WHAT MAKES A HEALTHY VILLAGE?

Focusing on values when building a circle of support is crucial because it ensures alignment with the fundamental principles guiding your loved one's care. By prioritizing these shared values, you create a nurturing environment where everyone's contributions are valued, leading to greater understanding, trust, and ultimately, improved outcomes for your child's well-being and development.

HERE ARE A FEW VALUES TO CONSIDER WHEN DETERMINING WHO BELONGS IN YOUR SUPPORT CIRCLE

DIVERSITY

Aim for diversity within your support circle to provide your loved one with a range of perspectives and experiences. This can include family and friends. However, consider individuals with relevant skills or expertise that could benefit your loved one, such as medical professionals, therapists, or educators.

COMMUNICATION

Select people who are effective communicators and can maintain open and honest dialogue with you about your loved one's progress and needs.

COMMITMENT

Choose individuals who are committed for the long term and willing to invest time and effort into supporting your loved one's growth and development. Also respect their time boundaries.

RELIABILITY & COMMITMENT

Look for people who are dependable and consistent in their actions and commitments. Choose individuals who are committed for the long term and willing to invest time and effort into supporting your loved one's growth and development. Be sure to discuss and respect their time boundaries.

VALUES ALIGNMENT

Choose individuals whose values align with yours and who will uphold the same principles in aiding your loved one. Never assume someone would go about caring for your loved one as you would. Prioritize those who have an understanding of disabilities and are willing to learn more about your loved one's specific condition. Ensure that those in your support circle respect your family's boundaries and privacy.

Who's part of your village? What role do they play?

THE CHALLENGES WITH ASKING FOR HELP

Many caregivers find it difficult to ask for help because they see it as an admission of weakness, undermining their perceived strength and capability. There is often a sense of guilt in admitting that the caregiving role is challenging and that there are tough days with the child or person in their care. This guilt can stem from a fear that others might interpret their struggles as a lack of love or commitment.

However, seeking help does not diminish the love and dedication caregivers have for those in their care; rather, it reflects a realistic understanding of the demanding nature of caregiving. Accepting support can enhance their ability to provide better care and maintain their well-being. Acknowledging the difficulty and seeking help is a sign of strength and self-awareness, not a lack of love or dedication.

1 Emotional Attachment

Strong emotional ties to the person they care for can make it difficult to admit they need help, as it feels like they are letting that person down.

2 Guilt

They may feel guilty for not being able to manage everything on their own and fear that admitting difficulties reflects poorly on their dedication.

3 Fear of Judgment

Concerns about being judged by others for not being able to handle their caregiving duties alone.

4 Cultural Expectations

Societal or cultural norms may emphasize self-reliance and stigmatize seeking assistance.

5 Burdening Others

They worry about imposing on friends, family, or community members, fearing they might be adding to others' responsibilities.

6 Stigma

There may be a stigma associated with needing help, especially in cultures or communities that value independence.

7 Lack of Awareness

They might not realize that support systems exist and are meant to be utilized.

8 Perceived Weakness

Asking for help may be seen as a sign of inadequacy or inability to cope with caregiving responsibilities.

WHAT DO THESE BARRIERS LOOK LIKE FOR BLACK CAREGIVERS?

1. **Historical Mistrust:** Historical and systemic mistrust of healthcare and social services can make Black caregivers hesitant to seek external help.
2. **Cultural Expectations:** Cultural norms may emphasize resilience and self-reliance, discouraging asking for assistance.
3. **Stigma and Stereotypes:** Fear of reinforcing negative stereotypes about Black families, such as being seen as incapable or dependent.
4. **Community Pressure:** Expectations from within the Black community to "handle things" internally and not seek outside help.
5. **Racial Discrimination:** Experiences of racism and discrimination in seeking help previously, leading to reluctance to reach out again.
6. **Economic Barriers:** Financial constraints and lack of access to affordable care resources may limit options for seeking help.
7. **Intersectional Burdens:** The compounded stress of dealing with both racial and caregiving challenges can make the process of asking for help feel overwhelming.
8. **Lack of Representation:** Limited representation of Black caregivers in support groups and services can make these resources feel less accessible or relevant.
9. **Fear of Legal Consequences:** Concern about potential involvement of authorities, such as child protective services, especially given higher rates of surveillance and intervention in Black communities.
10. **Invisible Labour:** The additional, often unrecognized, emotional and physical labour that Black caregivers might perform within their families and communities.

HOW TO GET HELP

Family Members

Relatives can provide practical assistance, emotional support, and respite care to help alleviate the caregiver's responsibilities.

Friends and Neighbors

Close friends and neighbors may offer assistance with daily tasks, transportation, or simply provide a listening ear when needed.

Community Organizations

Local disability advocacy groups, nonprofits, or community centers may offer resources, workshops, and support services tailored to the needs of caregivers and individuals with disabilities.

A note on paid support

It's important to recognize that not being able to afford paid support for long periods of time does not reflect negatively on the quality of care your loved one receives. Seeking help from professionals is just one avenue of support among many, and it's perfectly okay to rely more heavily on unpaid supports like family and friends when financial constraints are present. Mixing up the types of support you utilize allows you to accommodate both you and your loved one's needs more effectively, preventing over-reliance on any one avenue. For instance, there may be times when the expertise of professionals like behavioral or speech pathologists is necessary, while other times, emotional support from family members is more beneficial. Each type of support offers something unique, so it's essential to identify your needs and choose supports accordingly.

Therapists and Specialists

Accessing professional support from therapists, psychologists, or specialists can provide guidance and assistance in managing the unique challenges associated with caring for someone with a disability.

Paid Caregivers/ Respite Care

Hiring paid caregivers, such as personal care assistants or home health aides, can provide additional support and assistance with caregiving tasks, allowing caregivers to manage their responsibilities more effectively.

Support Groups

Joining support groups specifically for caregivers of individuals with disabilities can offer valuable peer support, shared experiences, and practical advice.

By having a mix of paid and unpaid support, caregivers can access a range of resources and assistance to meet the diverse needs of their loved one with a disability while also maintaining their own well-being and balance in their caregiving role.

1. What kind of supports do you use?
2. Think of all the supports you have accessed in the past few months. What combination of supports work best for you? Why?

MANAGING EXPECTATIONS

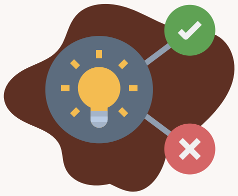
A note on unpaid support

Now that we understand the challenges of asking for help and how to overcome them, let's discuss managing support and maintaining healthy relationships with those in your circle. Managing expectations when seeking help in caring for someone with a disability is essential for both the well-being of the individual and the caregiver. Recognizing that responsibility cannot always be evenly distributed among those offering assistance is crucial, as everyone has different capacities and limitations.

How do you determine what to expect from those in your circle of support?

Explore Time Constraints

Recognize that availability may change. For example, an older cousin might help during school breaks but not during the academic year.



No Assumptions

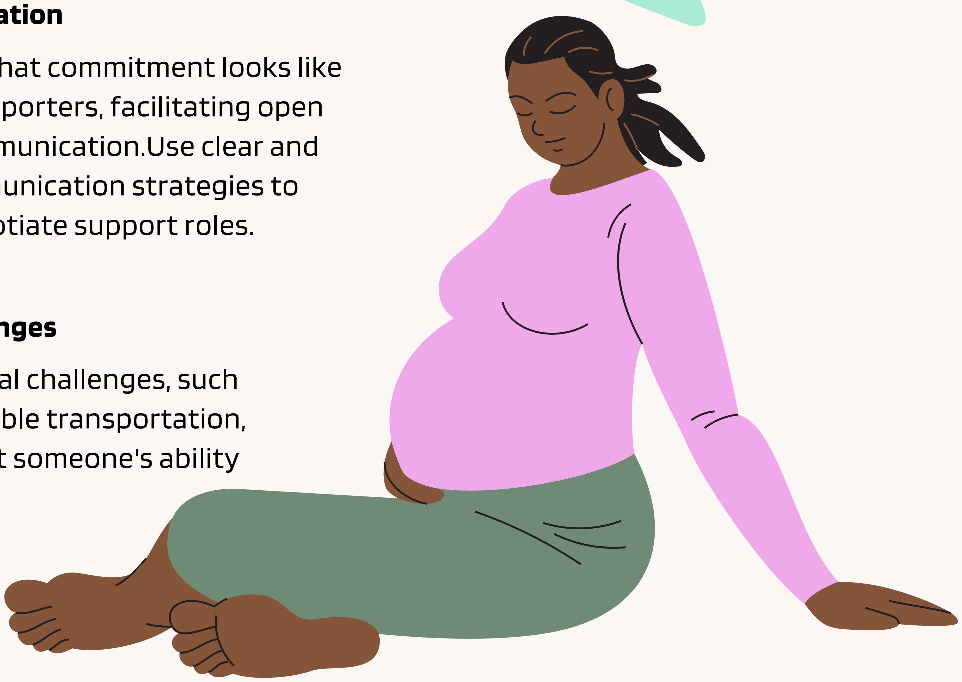
Do not assume someone should help you, even if they are family. Respect their autonomy and willingness to contribute.

Open Communication

Clearly outline what commitment looks like for potential supporters, facilitating open and honest communication.Use clear and respectful communication strategies to discuss and negotiate support roles.

Logistical Challenges

Consider logistical challenges, such as access to reliable transportation, that might affect someone's ability to help.



EXAMPLES OF DIALOGUE

The goal of communicating your need for help is to express your requirements and expectations with as much clarity and detail as you deem necessary. By being transparent about the type of assistance you're seeking, whether it's specific tasks, time commitments, or other expectations, you ensure that potential supporters understand the scope of their involvement.

Additionally, inviting discussion and negotiation allows both parties to openly address any concerns or constraints, fostering a collaborative approach to caregiving. This communication not only clarifies roles and responsibilities but also creates a space for mutual understanding and agreement, ultimately leading to a more effective and supportive care network.

1 Scenario 1: Requesting Support

"Hi [Name], I was wondering if you'd be interested in supporting me in this caregiving role. I need help with [specific tasks] for about [time duration] per week. What do you think about this? Is this something you can commit to?"

"Hey [Name], I hope you're doing well. I wanted to ask if you'd be willing to lend a hand with [specific tasks] for a few hours each week. It would mean a lot to me and [individual's name]. What do you think? Can you commit to helping out?"

2 Scenario 2: Discussing Time Constraints

Hi [Name], I know your schedule can be busy, especially during [specific time]. I'm looking for help with [specific tasks] during [specific period]. Can we discuss if there's a way you could assist during times that work for both of us?

Hey [Name], I know life can get hectic, especially with [specific time]. I'm looking for some extra support with [specific tasks] during [specific period]. Can we chat about how we can make it work around your schedule?

3 Scenario 3: Negotiating Terms

"Hi [Name], I could really use your help with [specific tasks]. I understand you've got your own things going on, so let's figure out a time and plan that works for both of us. How can we make this work?"

A FINAL NOTE ON COMMUNICATION

Asking for help and discussing expectations in detail takes courage. It's crucial to establish your needs honestly to find support that aligns well with you and the individual in your care. Clear communication and understanding both parties' limitations and capabilities ensure a supportive and effective care network.

The last time you asked for help how did it go? If you could re-do that situation what would you change?

GENDER & CARE

As caregivers, it's essential to be mindful of traditional gender roles, which come with specific expectations about who should perform certain tasks. Homemaking and child-minding are often seen as "women's work," but this rigid framework is unfair to both caregivers and the supported individual. These stereotypes limit the potential for shared responsibilities and fail to recognize the valuable contributions everyone can make. A more flexible and inclusive approach can benefit everyone involved.

Adaptability and Team Effort

As we learned in the self-care chapter, caregiving can be unpredictable, requiring adaptability. This unpredictability necessitates an "all hands on deck" approach, where time, commitment levels, and skills are considered when assigning tasks. Roles should remain flexible because caregiving is a team effort. By fostering this collaborative environment, we can prevent burnout and ensure that all tasks are managed effectively.

Breaking Stereotypes

Additionally, rigid gender roles unfairly paint men as incapable caregivers, even though they have much to contribute. Men can be excellent caregivers and should be encouraged to embrace this role without shame. Recognizing and expecting men to take on caregiving responsibilities helps dismantle harmful stereotypes and promotes a more equitable distribution of tasks.

BREAKING STEREOTYPES & RACIAL CONCERNS

Black fathers, uncles, youth workers, and community members all possess unique strengths and abilities that can significantly benefit both the child and the primary caregiver. In many cases, Black fathers and male relatives are actively engaged in caregiving but may not receive the recognition they deserve due to societal norms. However, their involvement should not be underestimated or overlooked. Breaking out of traditional gender roles is crucial, but it's important to recognize the additional complexities Black caregivers face due to racial stereotyping.

Consider this scenario

A Black man shared his hesitancy in dropping off his child at school because he was often viewed with suspicion and assumed to be a threat. Unlike other parents, he was questioned about his presence, a direct result of stereotypes portraying Black men as violent or absent fathers. This seemingly simple task becomes fraught with potential for conflict and escalation.

AN EXAMPLE OF ESCALATION

If he is assumed to be trespassing on school property, this may prompt someone to call law enforcement. The situation can quickly escalate, particularly if the child exhibits challenging behaviours (CB).

In his efforts to calm his child, the father might be perceived as aggressive or using excessive force, when he is simply trying to manage the situation.

KEY TAKEAWAY

When Black men choose to avoid certain caregiving tasks, such as school drop-offs, it is essential not to jump to conclusions that they see these tasks as "women's work." Their decisions may stem from a need to navigate and mitigate racial discrimination and its potential consequences.

Therefore, flexibility in gender roles should be accompanied by sensitivity to these racial dynamics. Always ask questions and seek to understand the reasons behind caregiving choices, rather than making assumptions.

Do you feel like there are expectations about how you should show up as a caregiver depending on your gender identity? Why or why not?

If yes, where do those ideas come from and are they helpful? What tasks do you feel comfortable doing and which do you not? Why?

EXPLORING THE FAMILY UNIT

In today's diverse and evolving society, it's essential to recognize that the traditional assumption of what a family "should" look like no longer reflects the reality for many individuals and communities. The outdated notion of the nuclear family as the standard model, consisting of two parents and their biological children living under one roof, fails to acknowledge the diverse array of family structures and relationships that exist. While every family comes with its own challenges, they are all valid and worthy of respect.

Single Parents/ Caregivers

Challenges: Limited support and resources, juggling caregiving duties with work and other responsibilities, financial strain.

Advantage: Direct decision-making authority, autonomy in caregiving decisions.

Blended Families

Challenges: Establishing new family dynamics, navigating relationships with ex-partners, coordinating schedules and responsibilities.

Advantage:Built-in support network, diverse caregiving roles and perspectives.

Same-Sex Couples

Challenges: Navigating societal stigma and discrimination, legal barriers to parental rights, lack of representation and support.

Advantage: Diverse perspectives and experiences, potential for shared caregiving responsibilities.

New Immigrant Families

Challenges: Language barriers, social isolation and disconnect from the support system back home, cultural differences in accessing services, immigration status affecting eligibility for support.

Advantage: Strong family bonds and community support networks, resilience in overcoming obstacles.

Multi-Generational Families

Challenges: Generational gaps in understanding disability, balancing caregiving roles between different generations, financial strain.

Advantage: Shared caregiving responsibilities, diverse skill sets and perspectives within the family unit.

The word family can mean many things , it truly goes beyond the nuclear family assumption. There are many intersections that determine how we form our families. Take time to think of yours with the questions to the right .

1. How do you define 'family'?
2. What type of family did you grow up in? In what way did this impact your expectations around parenthood?
3. How would you describe your family now? How does it differ from the one above?

SAFETY & CARE

Using discernment when accepting help is crucial for caregivers, as not all assistance is suitable for their loved one's needs or aligns with their values. While someone's intentions may be genuine, their capabilities or approach may not be the right fit for the individual's safety and well-being. Caregivers bear the responsibility of ensuring their loved one's safety, particularly as they are vulnerable individuals. Therefore, vetting potential help properly is essential. To ensure the safety of a disabled individual when seeking external assistance, caregivers should consider the following:

- ✓ Conduct background checks and verify credentials of potential caregivers or professionals.
- ✓ Ask for references and follow up with previous clients or employers.
- ✓ Trust your instincts and be prepared to advocate for your loved one's best interests, even if it means declining help that doesn't feel right.
- ✓ Observe how the potential helper interacts with your loved one and assess their ability to handle challenging situations.
- ✓ Establish clear boundaries and expectations regarding care routines, communication, and emergency procedures.
- ✓ Clearly communicate your loved one's specific needs, preferences, and any safety concerns.

NOT ALL HELP IS GOOD HELP!

What causes caregivers to overlook red flags when bringing in support for their loved one? What happened? How could it have been prevented?

How To: REJECT HELP

When rejecting help politely from individuals who are not a good fit for the individual's needs, it's essential to communicate respectfully while asserting your loved one's best interests. Begin by expressing gratitude for their willingness to help, then politely explain that their approach or qualifications may not align with what your loved one requires. Offer reassurance that you will continue searching for suitable assistance and leave the door open for future opportunities to collaborate. Here are three examples of how to reject help politely:

TRY THESE STRATEGIES

Express Appreciation and Clarify Needs

"Thank you so much for offering to help with [individual's name]. I truly appreciate your kindness. However, I've realized that [explain specific concern or mismatch]. Right now, we're focusing on finding support that aligns more closely with [individual's] needs. I hope you understand, and I'll keep you updated on our search."

Acknowledge Good Intentions and Set Boundaries

"I'm grateful for your willingness to lend a hand with [individual's name]. It means a lot to me. After careful consideration, I've realized that [explain reason for mismatch]. For now, we're exploring other options that better suit [individual's] requirements. Thank you for your understanding and support."

Offer Future Opportunities & Maintain Positivity

"Thank you for offering your assistance with [individual's name]. Your willingness to help is truly appreciated. However, I've come to realize that [explain reason for mismatch]. I'll definitely keep you in mind for future opportunities that may be a better fit. Thanks again for your understanding."

Have you had to reject help? How did it feel?

NAVIGATING SYSTEMS &
ADVOCACY

Self-advocacy and advocacy for others are indispensable skills essential for personal empowerment, social justice, and community building. Learning to assertively communicate one's needs, boundaries, and rights not only empowers individuals to navigate life's challenges effectively but also fosters confidence and self-esteem. By advocating for oneself, individuals gain access to necessary resources, support, and accommodations, particularly crucial for marginalized communities facing systemic barriers.

- Additionally, advocating for others promotes social justice and equality, contributing to a more inclusive society. These skills also play a vital role in leadership development, conflict resolution, and building alliances to address common challenges. Ultimately, self-advocacy and advocacy for others are about promoting fairness, respect, and dignity for all, driving positive change towards a more compassionate and equitable world.

THE IMPORTANCE OF ADVOCACY

In a society where systemic inequalities persist, Black individuals with disabilities often face additional barriers and discrimination that can impact their access to necessary services and support. Therefore, empowering caregivers with advocacy skills is essential to ensure that their loved one receive the care, resources, and opportunities they deserve.

What you gain when you learn to advocate

- **Empowerment**: Self-advocacy gives you the power to voice your needs, preferences, and concerns effectively. It helps you take control of your life and make informed decisions.
- **Assertiveness:** Learning to advocate for yourself teaches you how to assertively communicate your boundaries and rights without being aggressive or passive. This skill is invaluable in personal and professional settings.
- **Access to Resources:** By advocating for yourself, you can access the resources, support, and accommodations you need to thrive. This is particularly important for individuals with disabilities, marginalized communities, or those facing systemic barriers.
- **Building Confidence:** Advocating for yourself and others builds confidence and self-esteem. It reinforces the idea that your voice matters and that you have the ability to affect change.
- **Community Building**: Advocacy often involves building networks and alliances with others who share similar goals and values. It fosters a sense of community and solidarity, strengthening collective efforts to address common challenges.
- **Conflict Resolution:** Learning to advocate for yourself and others also involves conflict resolution skills. It teaches you how to navigate disagreements and negotiate solutions that are fair and mutually beneficial.

EXAMPLES OF ADVOCACY

Learning how to navigate within different social systems, such as education and healthcare, through the use of advocacy is crucial for Black caregivers of disabled individuals. In a society where systemic inequalities persist, Black individuals with disabilities often face additional barriers and discrimination that can impact their access to necessary services and support. Therefore, empowering caregivers with advocacy skills is essential to ensure that their loved one receive the care, resources, and opportunities they deserve.

In Education

- ✓ **Discrimination:** Black disabled children may be disproportionately placed in special education classes or face lower expectations from teachers due to stereotypes.
- ✓ **Lack of advocacy:** Without advocacy, caregivers may struggle to challenge discriminatory practices or secure appropriate accommodations for their child, leading to academic underachievement and limited opportunities for success.

Advocacy Strategies

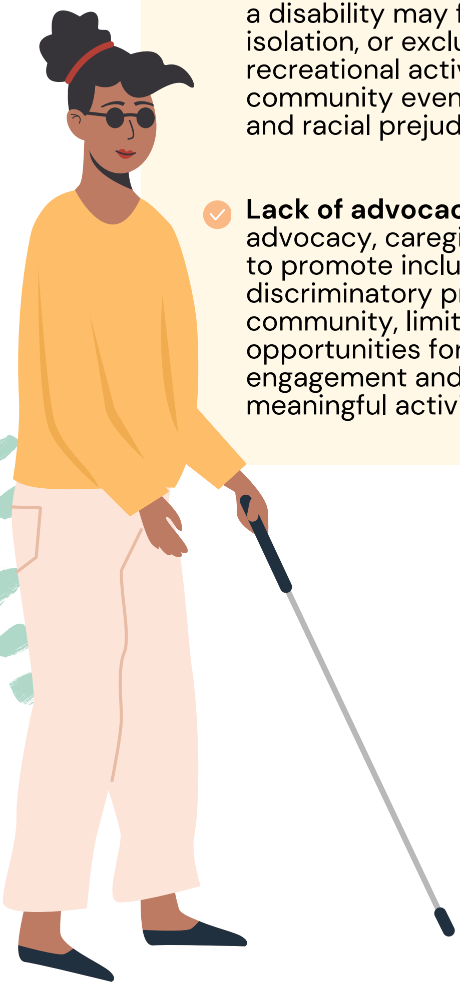
- ✓ Request a meeting to address concerns about classroom placement and the possible need for an Individualized Education Plan (IEP). Advocate for the best fit program: either an inclusive classroom setting that provides appropriate support or a small special education intensive program. Work out a way to partner with the school to track the progress of your child with this support and make amendments to the teaching plan as needed.
- ✓ Collaborate with teachers and school administrators to develop culturally responsive teaching practices that recognize and celebrate the strengths and abilities of Black disabled students.
- ✓ Seek support from advocacy organizations or legal services specializing in education law to challenge discriminatory practices and ensure compliance

In Healthcare

- **Discrimination:** Healthcare providers may exhibit bias, leading to diagnostic delays, inadequate treatment, or dismissive attitudes toward Black disabled children and their families.
- **Lack of advocacy:** Without advocacy, caregivers may feel powerless to challenge discriminatory practices or demand culturally competent care, resulting in compromised health outcomes and increased disparities in access to healthcare services.

In Community

- **Discrimination:** Black people with a disability may face social stigma, isolation, or exclusion from recreational activities and community events due to ableism and racial prejudice.
- **Lack of advocacy:** Without advocacy, caregivers may struggle to promote inclusivity or challenge discriminatory practices in the community, limiting the individual's opportunities for social engagement and participation in meaningful activities.

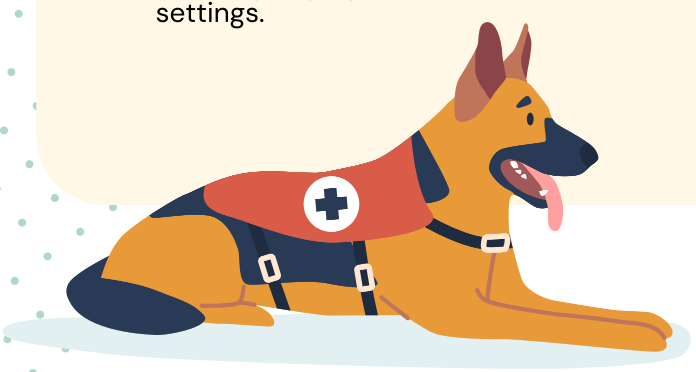


Advocacy Strategies

- Advocate for comprehensive assessments and evaluations to ensure accurate diagnosis and timely access to appropriate interventions and support services.
- Request culturally competent care and seek out healthcare providers who have experience working with diverse populations and understand the unique needs and perspectives of Black disabled patients.
- Document instances of discriminatory treatment and file complaints with relevant regulatory agencies or professional organizations to hold healthcare providers accountable and advocate for systemic changes to address bias and improve healthcare equity.

Advocacy Strategies

- Organize community awareness events or workshops to educate others about disability rights, inclusion, and the importance of creating accessible and welcoming spaces for all individuals.
- Advocate for policy changes and funding initiatives to support the development of inclusive recreation programs, accessible facilities, and opportunities for social engagement for Black disabled individuals and their families.
- Form partnerships with local community organizations, advocacy groups, and government agencies to advocate collectively for the needs and interests of Black disabled individuals and promote diversity, equity, and inclusion in community settings.



ADVOCACY CHECKLIST

- ☑ **Identify Specific Needs:** Clearly outline the individual's unique needs, challenges, and preferences to effectively advocate on their behalf.
- ☑ **Educate Yourself:** Stay informed about relevant laws, policies, and resources related to disability rights and services to better steer advocacy efforts.
- ☑ **Establish Clear Communication Channels:** Ensure open lines of communication with key people, including healthcare providers, educators, therapists, and community support organizations.
- ☑ **Document Everything:** Keep detailed records of meetings, conversations, and correspondence related to your loved one's care and advocacy efforts, including dates, participants, and outcomes.
- ☑ **Seek Support Networks:** Connect with other caregivers, advocacy groups, and support organizations to share experiences, gain insights, and amplify collective advocacy efforts.
- ☑ **Collaborate with Professionals:** Partner with healthcare professionals, educators, and service providers to develop comprehensive care plans tailored to the individual's needs and goals.
- ☑ **Know Your Rights:** Familiarize yourself with your loved one's rights under relevant laws and advocate for their full inclusion and access to services.
- ☑ **Persist and Follow Up:** Advocate persistently for necessary accommodations, services, and supports, and follow up regularly to ensure that agreed-upon actions are implemented and goals are met.

TOWARDS A HOPEFUL
FUTURE

"Towards a Hopeful Future" is the final chapter of our handbook, featuring stories from real caregivers who share their lived experiences. These narratives help put all the information from the handbook into perspective, making it more relatable and understandable. By including these personal stories, we aim to provide insights on how to apply what was learned throughout the handbook. Through these shared experiences, caregivers are empowered to advocate for their loved ones, even when faced with barriers.

This chapter is a reminder that you are not alone in your struggles. The journeys shared by others demonstrate the strength and resilience within the caregiving community. Lean on these stories for inspiration and guidance, and remember to reach out and connect with others who can support you. Building a network of understanding and compassionate individuals can make a significant difference in your caregiving experience, fostering hope and solidarity as you navigate this challenging path.

TOWARDS A HOPEFUL Future

A. A.
COPING THROUGH FAITH

I am a caregiver and mother to a wonderful teenager who has taught me how to love, care, and extend myself to others. J. is autistic and his challenges are many. Managing hormonal levels, anxiety and agitation takes caring to a whole new level. Dealing with school, home, therapy and outdoor life can be quite stressful and overwhelming at times.

I am very excited to have a practical and informative Caregivers Handbook to help me navigate my way through the system. Anything to make our lives less stressful is great!

I am grateful to the team that put this lifesaver together.

I am learning to put my trust in God, asking Him for wisdom, knowledge and understanding to care for this wonderful son of mine. God has proven Himself faithful over and over again. Thank you all for caring for caregivers, we appreciate you.

TOWARDS A HOPEFUL Future

P & G
GROWING WITH AUTISM

As the caregiver of a person with special needs, the challenges are never-ending. Our son was diagnosed with autism at the age of three. He is now almost forty-three. We have been through the school system and have had both good and bad experiences. I like to focus on the 'good' and I do count my blessings for the support assistant he had at that time. It was her first job and we received nothing but the best from her. She has remained a family friend of ours and comes to visit once a year.

High school was very basic. They tried (with every good intention) to get my son involved in the recycling program. The result was horrendous. No matter where we went J would always want to clean-up and recycle. We still have a hard time stopping him sometimes.

J is now at an adult day program where he is safe and happy. They recently hired new staff with new ideas etc. and he is enjoying the program.

J is older now and so are we. We now face our biggest challenge of thinking about who will care for our son when we are no longer around.

I am glad for the formation of Sawubona and for all the various ideas and discussion groups they have been able to provide over the years. I have benefitted immensely from them. P & G

TOWARDS A HOPEFUL Future

C.R.
CAREGIVING & SINGLE MOTHERHOOD

Being a single mother to my two wonderful children, a 13 year old son on the autism spectrum and an 11-year-old daughter, presents unique challenges and rewards every day. Life can be incredibly demanding, especially when I have to manage everything on my own. My son's behavior can sometimes be unpredictable and aggressive, often for reasons beyond his control. In these moments, it can be especially tough, but I know that staying strong is crucial for the well-being of our family. Balancing the needs of both my children requires patience, resilience, and unwavering love.

Despite the hardships, I am committed to creating a nurturing and supportive environment for them. My daughter and I work as a team to bring out the best in my son, celebrating his progress and supporting him through his struggles. We navigate the ups and downs together, finding strength in our unity and determination. Every day is a testament to our resilience and dedication. We face each challenge head-on, knowing that together, we can overcome any obstacle. My children are my inspiration, and their growth and happiness are my greatest rewards. Our journey may be tough, but it is also filled with love, hope, and the unwavering belief that we can achieve great things as a family and with my God's strength and support that he gives us. I give all honours and praise to God for the courage.

TO OUR READERS

On a final note,

putting together a document like this would not have been possible without a collective effort. To the families-- thanks for allowing us to share your stories; to our team lead on this project Esther- thanks for your excellent work in capturing the narratives shared by the families; to Khyara, thanks for using your brilliance and creativity in documenting this all in such an engaging and readable format; to my wife Sherron, our founder and leader, thanks for your inspiration in wanting to make such a document available to our families. Finally, thanks again to the Canadian Red Cross Society Community Services Recovery Fund for your generous funding allowing us to embark upon this work.

With such a great initiative completed, it is not meant for a shelf or to be stored away as an electronic file on our computers....it belongs in the hands of people. It is to be shared, distributed, talked about and used to Empower, Educate and Enlighten the community--- not just the families but those who work with and support Black families caring for a loved one with a disability.

While we have done our best to be as comprehensive as we can with identifying the essentials for caregivers, we know that we may have overlooked other important elements. On that note, we welcome your feedback....and who knows, a future edition may follow. Please visit us at www.sawubonaacs.org and let us know your thoughts.

Clovis Grant
Co-Founder
Sawubona Africentric Circle of Support

Sawubona Africentric Circle of Support (Sawubona) was created to serve Black families across Canada. This parent/caregiver handbook is geared towards Black families and caregivers in Ontario, but the information and principles can be applied in any community where there are Black parents/caregivers and the individuals they support.

GLOSSARY

Accessibility	Easily used or accessed by people with disabilities : adapted for use by people with disabilities whether in the short or long term.
Accessibility for Ontarians with Disabilities Act (AODA)	The Accessibility for Ontarians with Disabilities Act (AODA) is a law that sets out a process for developing and enforcing accessibility standards. Persons with disabilities and industry representatives work together with the government to develop the standards. The four underlying principles of the Act include: independence, dignity, integration and equality of opportunity.
Africentric/ Afrocentric	Focusing on or influenced by Africa or cultures of African origin; focusing on persons of African descent as agents in their own contexts; grounded in the values, worldviews, lived experiences and histories of Black people of African descent.
Advocacy	The act or process of supporting a cause or proposal : the act or process of advocating.
Anti-Black Racism	Policies and practices rooted in Canadian institutions such as, education, healthcare, and justice that mirror and reinforce beliefs, attitudes, prejudice, stereotyping, and/or discrimination towards people of Black/African descent.
Caregiver	A person who provides direct care (e.g., as for children, elderly people, or the chronically ill). They can be both paid and unpaid, a family member or friend.
Circle of Support	A Circle of Support is a group of people who you invite to give you guidance and support and to help you plan for your future and/or that of your loved one.
Cultural Safety	Focuses on creating and nurturing an environment where people feel safe to be their authentic self. An environment of shared knowledge and respect.
Discrimination	The practice of treating similarly (socially) situated individuals differently and negatively because of race, gender, sexual orientation, appearance, or national origin. The unjust or prejudicial treatment of different categories of people, especially on the grounds of ethnicity, age, sex, or disability.
Identification , Placement and Review Committee (IPRC)	An IPRC is a committee at the child’s school that meets and decides if a student should be identified as exceptional (has additional needs) according to established Ministry of Education categories. An IEP is all about personalizing support for your child, while an IPRC ensures the right educational placement for exceptional students.
Identity	On a personal level, identity often refers to a person's sense of self, meaning how they view themself as compared to other people.

GLOSSARY

Inclusion	The act or practice of including and accommodating people who have historically been excluded (for example because of their race, gender, sexuality, or ability).
Individual Education Plan (IEP)	An Individual Education Plan (IEP) is a written plan that describes Special Education programs, accommodations and services that a school board will provide for a student. IEPs are based on a thorough assessment of a student's strengths, needs and ability to learn and demonstrate learning.
Intersectionality	It is the study of overlapping or intersecting social identities and related systems of oppression, domination, or discrimination. Intersectionality is the acknowledgement that everyone has their own unique experiences of discrimination and oppression and we must consider everything and anything that can marginalize people – gender, race, class, sexual orientation, physical ability, etc. For example, an individual may identify as Black, Queer and Disabled. These are intersecting identities.
Respite	A short period of rest or relief from something difficult or unpleasant.
Self-advocacy	Self-advocacy is the ability to speak up for yourself and the things that are important to you. You are able to tell people about your thoughts and feelings. You are able to ask for what you need and want. You know your rights and you speak up for your rights.
Self-efficacy	An individual’s belief in their capacity to act in the ways necessary to accomplish their goals.
Self-care	The practice of taking an active role in protecting one's own well-being and happiness, in particular during periods of stress.
Stigma	A mark of disgrace associated with a particular circumstance, quality or person. Stigma is when someone sees you in a negative way because of a particular characteristic or attribute (e.g., such as skin colour, cultural background, a disability or mental illness).
Stereotype	A stereotype is a widely held and fixed general image or set of characteristics, often negative, that a lot of people believe represent a particular type of person or members of a group.
Trauma	The word “trauma” literally means wound, shock, or injury. Psychological trauma is a person’s experience of emotional distress resulting from an event that overwhelms the capacity to emotionally digest it. Trauma is the lasting emotional response that often results from living through a distressing event.

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