

Caregiver Healing Journal

Volume II: Naming



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Mothers on the Frontline is non-profit organization. Our mission is to promote children's mental health justice, caregiver justice, and caregiver healing through storytelling. Our vision is a world in which all children are safe and able to thrive because their unique educational, social, emotional and health needs are genuinely met.

Acknowledgements:

We would like to thank all of the mothers, caregivers, educators, and children's mental health professionals who have shared their stories through consultations, podcast interviews, and attending our workshops. Your stories have informed the prompts in this journal. We would like to give special gratitude to Susan Sanning for co-creating and co-facilitating a caregiver workshop with us in the summer of 2023 that further refined some of the material and Sage Gladstone, a volunteer through the Grinnell College Service Leadership Work-Study Program for her contributions to the design and lay out of many of the pages.



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This journal is dedicated to
all who mother children with mental health conditions.

We see you.

We know that your child is not your burden,
they are your joy.

Your burden is a world
that was not designed for your child,
a world that can be cruel and uncaring
to your child
and to you.

We see you navigating
this world
with your child,
for your child.

We know the isolation, the pain, the worry.

You are not alone.



Who We Are

At our most fundamental level we are three close friends who share the lived experience of parenting children with mental health conditions, neurodevelopmental disorders and other complex medical needs. It was from our many conversations that we discovered the commonality of the damaging and traumatic experiences our families endured as we did everything in our power to get accurate diagnoses, inclusive education, and access to scarce services and treatment for our children.

Our friendship served to protect us against the isolation and hopelessness that overwhelms many parents, caregivers and families in our situation. We helped each other recognize and name the things that were happening to us. We understood each other's fear, pain, anger, love, hope and joy in ways that only those with the same lived experience can truly know. We helped the others feel seen, heard and respected. Often for the first time. We helped each other heal.

We would not have survived without the love, support and the unique wisdom of the others.

Eventually, our conversations took on a different direction and we moved from how do we support each other to how do we best share what we've learned with others? From this sisterhood of survival Mothers on the Frontline was born.

Mothers on the Frontline is the first Children's Mental Health Justice focused organization. We are a 100% volunteer run. Our work aims to address and transform the long standing social, structural, and institutional injustices that harm our children, their caregivers, families and communities.



Invitation For Solidarity With All Mothers

All people have the right to mental health care and mental well-being.

Mental health is a vital, integral part of the overall health and well-being of ALL children, families and communities.

All children with mental health conditions, their parents and caregivers, have the right to genuinely healing care and support that centers the expertise, wisdom and experiences of our children, families and communities.

We envision a world in which mental health is destigmatized, respected and prioritized.

We disrupt deeply entrenched narratives of motherblame, particularly the narratives surrounding motherhood of children with mental health conditions, through the healing power of storytelling.

We identify the structures, ideologies and practices that create obstacles to fully, effectively and compassionately care for our children, and identify the active harms that underpin much of our ill-being.

We imagine a world in which our children, families and communities are safe, valued, understood and respected. A world in which our children thrive because their unique educational, social, emotional and health needs are genuinely met. We imagine a world in which their beauty, joy, love, compassion and talents are the focus of their and our existence.

We could not do this healing work without the sacrifices, blood, sweat, tears, wisdom, and knowledge shared with us by trans-queer folx, people with disabilities, Black, Indigenous, and other People of Color and especially the women of these movements, our ancestors, mothers, grandmothers, aunties, sisters and friends.

We are humbled by their grace, fortitude, strength, kindness, and love and strive to uplift their voices with this work.

In the spirit of reciprocity and mutual responsibility we invite you, your families, communities and ancestors to join us on this journey of discovery, transformation and healing.



Purpose of Journal

As your child's advocate, you spend so much time trying to help others understand your child's needs, it's all too easy to forget your own. This journal is not about your child, though you will write about and reflect on your journey caring for your child. This journal is about *you*, because you *matter*.

You matter.

Take a moment to take that in.

You and your life matter - full stop.

This journal is about you, *your* story, *your* lived experience, *your* wisdom. Your story is connected with your child's - but your story is *not* your child's story.

That belongs to them. Your story belongs to you.

How To Use Journal

This journal is divided into four sections that invite you to:

- Gather yourself
- Name your experiences
- Reclaim your story and wisdom
- Re-imagine expansively

Do what feels good for you. Write some, draw some, imagine some, dance some. Talk to a friend. Take some time and allow your thoughts to rise and fall. Take some rest. Breathe and just be.

This is an invitation to put aside a special time to reflect and write - whatever you can manage in the context of your life. We do not recommend powering through the whole journal at once. Give yourself time to let each writing sink in. There is no right or wrong way, there is just the best way for you. If you are interrupted, remember that is part of this journey - note it down and continue when possible. If you cannot take time to write, peek at the prompt and allow your mind to make a space for reflection as you do your tasks of the day. This is all about you making space for you.

These exercises are meant to be done individually. They are designed to center yourself and be present with your own thoughts and feelings, your own stories. However, you might chose to meet with a support group or gathering of other caregivers to discuss and share what arises for each of you after individually completing each section.





Before each writing or sharing session, we invite you read aloud the Invocation of Healing and do a grounding exercise.

Invocation of Healing

When I am healed I feel
seen, heard and respected.

When I am healed I am connected
to myself, my children, family
and community.

When I am healed I am grounded
in my body, my spirituality, my knowing.

When I am healed I embody
the joy, love, trust,
surprise, curiosity
and pleasure
of my humanity, relationships and caregiving.

When I am healed I am whole.



MOTHERS ON THE FRONTLINE

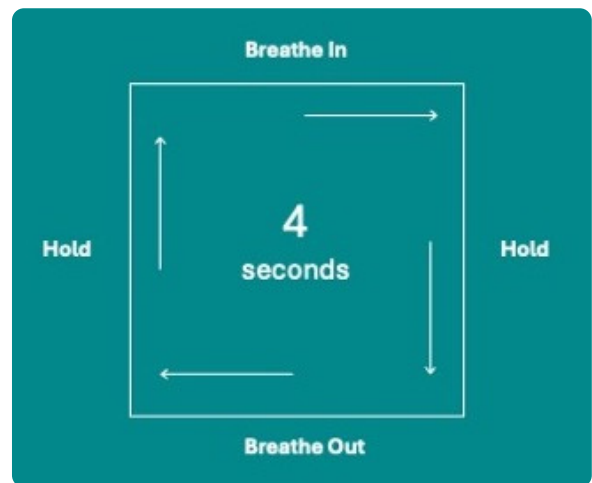
Grounding Activities

Why do a grounding activity? This work involves a great deal of emotional labor and it is important that we care for our minds and bodies as we do it. Grounding activities help us settle our mind and be present in our body. An example of a grounding activity is provided below. Feel free to use any method of grounding that feels right to you.

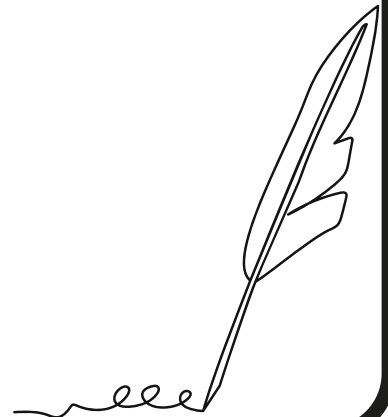
Get comfortable. This is the time to put any devices on Do Not Disturb. Take a few moments to get situated into your space. Grab a pillow, a sweater, a cup of tea and anything else that you might need to be comfortable and settled.

Box Breathing

1. Breathe out slowly, releasing all the air in your lungs.
2. Breathe in through your nose while you slowly count to four in your mind. Be aware of your stomach rising.
3. Gently hold your breath for a count of four.
4. Gently exhale for a count of four.
5. Gently hold your breath again for a count of four.
6. Repeat three or four times.



What other grounding activities have worked well for me in the past or would I like to try?



Introduction to Naming

Have you ever experienced a time when you knew something was wrong but you just couldn't put your finger on it or find the right words to describe what was happening to you? In this volume we are going to give words to those unnamed things.

Words have power. They can harm and they can heal.

Here we will make visible the invisible. Whether that be our pain, fears, our work, or stories.

Here we disrupt the harmful stories we have been told and absorbed about mental illness and mothering.

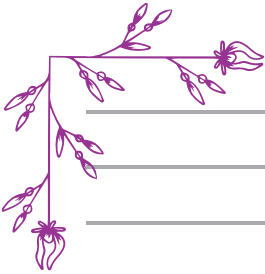
Here we break free of the isolation and stigma surrounding mental illness.

Here we identify the structures, ideologies and obstacles that harm us, our families and our communities. We put words to the things that prevent our children from being treated with compassion and experiencing genuinely healing care.

Here we name our challenges. We bring forth our wounds so they may be healed. We celebrate our beauty and that of our children. We share our joy.

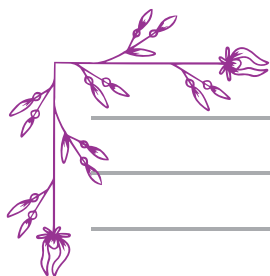
Here we find our voice. And maybe that helps us to find courage, connection and community with others who share our lived experiences.

What are your greatest joys mothering your child/children?



Lined area for writing responses.

What challenges do you encounter mothering your child/children?



Lined area for writing responses.

Reflect on your experiences advocating with and on behalf of your child. Draw a picture or list the words that best describe how things are or have been in each area.

School

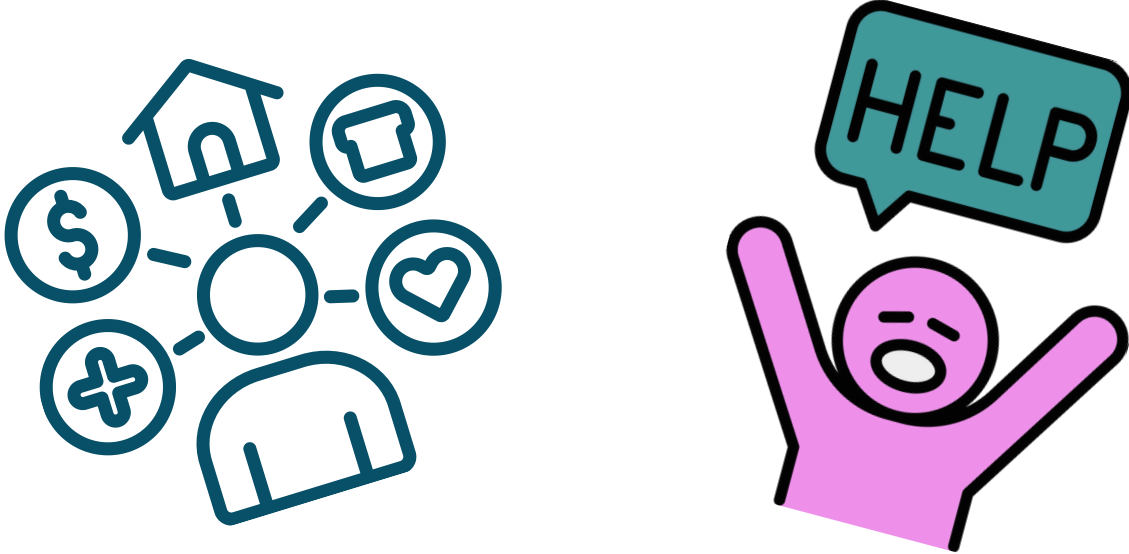
Healthcare

Reflect on your experiences advocating with and on behalf of your child. Draw a picture or list the words that best describe how things are or have been in each area.

Services within the Home & Community

Recreational & Social Opportunities

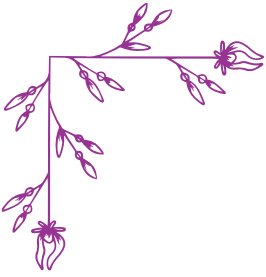
Naming Needs



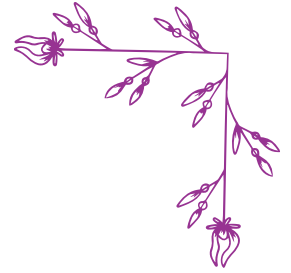
Being able to name our needs is an important first step to getting those needs met. We live in a world that was not designed for persons with disabilities or their caregivers. It can be a daily fight to get our most basic needs met. We are often functioning in ‘survival mode’.

Timed Exercise (pages 16-30)

Set aside at least 30 minutes and a timer (you can use the stopwatch feature on your phone. We recommend turning your phone to “do not disturb”). Set the stopwatch for 1 minute. You will brainstorm answers to a series of prompts, giving each prompt one minute. This is meant to be quick and non-reflective. (Don’t worry about the number of lines you fill, just write whatever you can in that minute.) Afterwards, you will have time to reflect on what you wrote. We recommend you do these exercises when you have the time and ability to care for yourself afterwards, for example, take a walk or chat with a friend.



**Set the clock for a one-minute brainstorm
(then quickly move on to the next page)**



In order to care for others, I have put aside...



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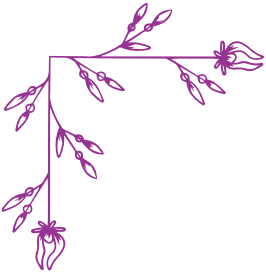
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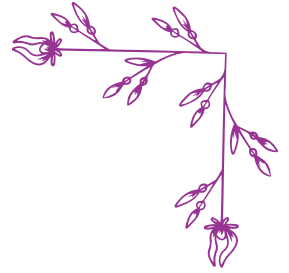
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**Set the clock for a one-minute brainstorm
(then quickly move on to the next page)**



Putting these things aside has resulted in...



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












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Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

I have lost...

Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

I have gained



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












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Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

I have let go of

Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

A silence that needs to be broken is

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Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

My survival habits are ...

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Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

I have to start saying 'no' to ...



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











**Set the clock for a one-minute brainstorm
(then quickly move on to the next page)**

When I say 'no' it matters because...

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Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

I have to start saying 'yes' to...














**Set the clock for a one-minute brainstorm
(then quickly move on to the next page)**

When I say “yes” it matters because...

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Set the clock for a one-minute brainstorm
(then quickly move on to the next page)

I matter because ...

Taking Notice

Take 2 minutes to review your responses on pages 16-27.



**Take 3 minutes to name
anything that surprised you.**



**Take 3 minutes to name the feelings
in your body right now.**

Set your stopwatch to 5 minutes to answer this prompt:

What needs of yours are being met and how?

What and who are you grateful for?

[illegible]

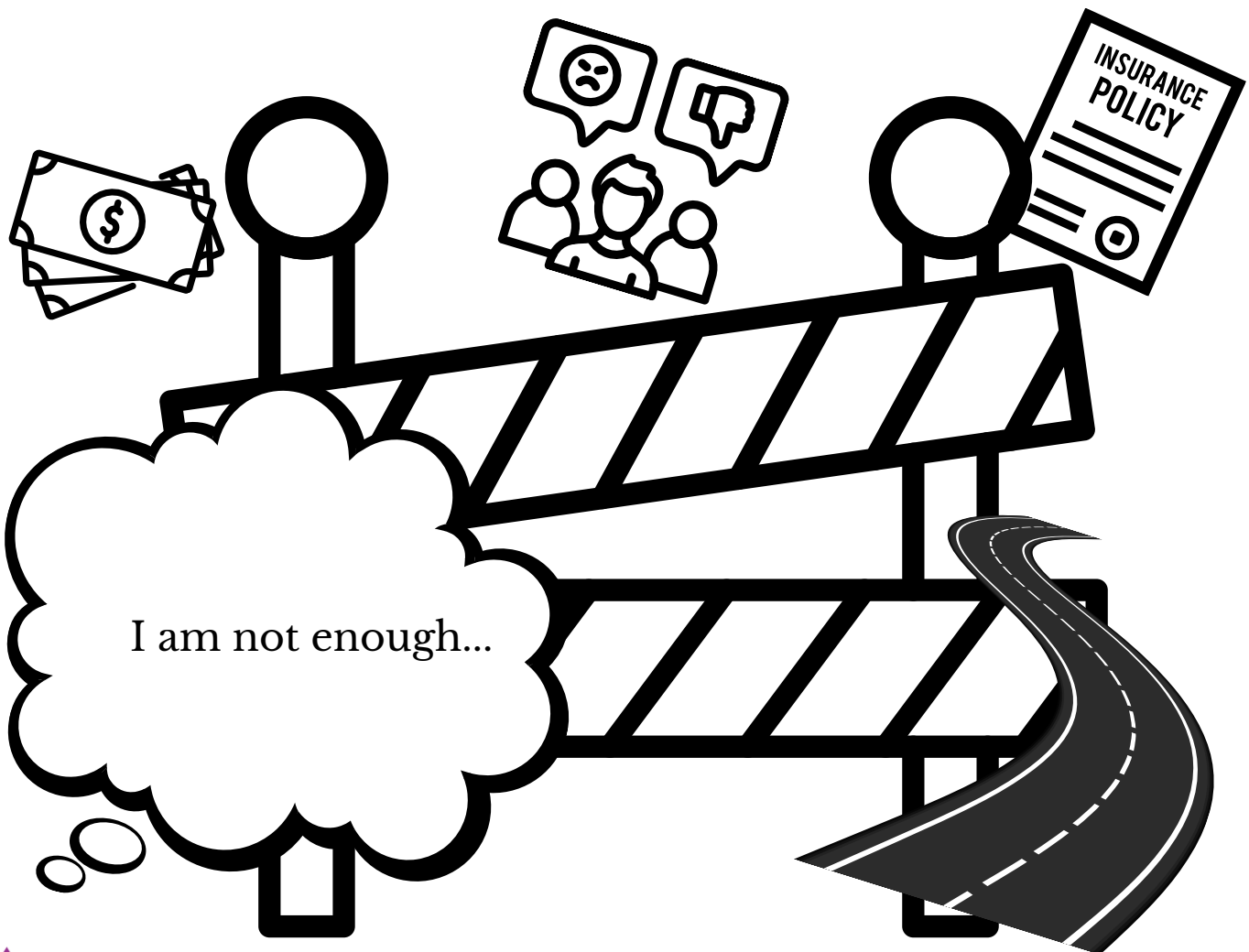
[illegible]

Feel free to use this space if you want or need to write more in an untimed fashion after the timed exercise.

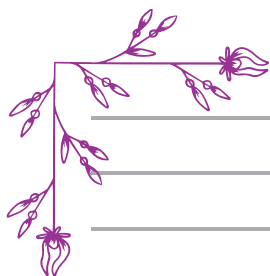
[illegible]

Naming Obstacles

Sometimes simply being able to name and ask for what we need is enough. Unfortunately this often is not the case. There are many obstacles we face as caregivers. We often have to navigate parts of the world that are not designed for our children or the kind of caregiving they need. Sometimes we are forced to navigate parts of the world that are downright hostile to our families. Obstacles can block our way. We live in a world in which care labor is often made invisible and exploited. As mothers, we often internalize damaging tropes about mother blame. In an ableist world, our families often encounter stigma and prejudice on a daily basis. We may find financial barriers, insurance barriers, geographic barriers, etc., between us and the services our families desperately need. This section is about naming obstacles you face in trying to meet your needs and the needs of those you care for.



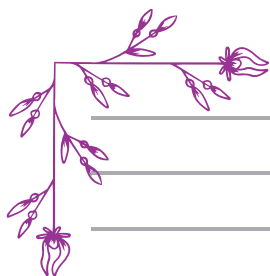
What obstacles prevent your child from receiving the education they need at school?



A series of horizontal lines for writing, spanning the width of the page below the question.



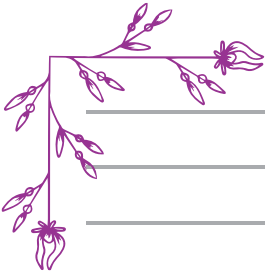
What obstacles prevent your child from receiving the health care they need?



A series of horizontal lines for writing, spanning the width of the page below the title.



What obstacles prevent your child from full inclusion in the community?



Lined area for writing responses.



One person alone cannot meet all of your child's needs. What obstacles stand between you and the support you need as a caregiver in the areas of education, healthcare, and / or community involvement? (An extra page is provided if needed.)



A series of horizontal lines for writing, starting from the top of the page and extending down to the bottom, providing space for the user to answer the question.



[illegible]

Perceptions

Our experiences are colored by how we perceive ourselves and how we anticipate others will perceive us. These perceptions frame our thoughts, beliefs, and feelings. They also shape our expectations— both of ourselves and of others.

Such perceptions can hold an invisible power over us—until we name them, examine them, and determine if those perceptions are accurate. Are they coming from an informed view, or based on stigma, stereotype or prejudice?

Naming is important for healing. It helps us tend to wounds from internalizing inaccurate and unfair perceptions that others have of us. It helps us prevent such wounds in the future.

Naming is also important for strategizing. When we are able to name perceptions we regularly encounter that are inaccurate and unfair, we are better prepared to intentionally strategize how we navigate the world with and for our child.

Naming also helps us face hard truths of our reality and better recognize others sharing those hard truths so we can support each other with recognition, love, and solidarity.

Naming is a super power—it helps us see things as they are.

Perceptions—our own and those of others, can become obstacles as we try to navigate systems with and on behalf of our child. Such perceptions can involve assumptions others make based on our or our child’s identities, personalities, or circumstances. Underline those that come up in your caregiving journey. Use one color pen for yourself and another for your child. Fill in any that are missing.



This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There is a small purple mark or smudge in the top left corner. The paper appears to be part of a notebook or a set of loose-leaf papers.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There is a small purple mark or smudge in the top left corner. The paper appears to be part of a notebook or a set of loose-leaf papers.

How are you and your child similar? How are you different? Write the similarities and differences that come up the most when navigating the world with and on behalf of your child. Give some examples.

A Venn diagram consisting of three overlapping circles. The top-left circle is labeled "Me", the top-right circle is labeled "My child", and the central overlapping area is labeled "Both of us". The circles are outlined in a thick grey line. Below the diagram, the word "Examples" is centered.

Me

My child

Both of us

Examples

How do your shared and different identities affect how others treat the two of you when seeking services and supports?



Lined area for writing, consisting of 25 horizontal lines.



[illegible]

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are approximately 20 lines visible. In the top left corner, there is a small purple decorative element resembling a flower or a swirl. In the top right corner, there is a small purple arrow pointing upwards. The paper appears to be part of a notebook or a binder.

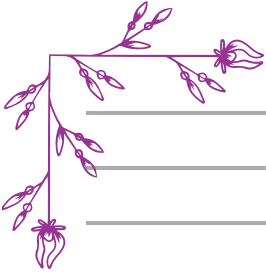
This image shows a single sheet of white paper with horizontal grey ruling lines. The lines are evenly spaced and run across the width of the page. In the top-left corner, there is a small, stylized purple graphic that resembles a paperclip or a decorative element. The paper appears to be part of a notebook or a set of stationery.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There is a small purple mark in the top left corner and a small pink mark in the top right corner. The paper appears to be part of a notebook or a set of loose-leaf papers.

[illegible]

[illegible]

Go back and read your writings in in this section. To what extent are perceptions contributing to the obstacles you mention on pages 33-37?

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and extend across the width of the page. There is a small purple mark or smudge in the top left corner. The paper appears to be part of a notebook or a set of stationery.

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