



Parent Advocacy and Self-Care Workbook





- ✓ Identifying Barriers
- ✓ Communicating Needs
- ✓ Goal Setting
- ✓ Self-Care
- ✓ Resources









This workbook provides advocacy and self-care tools and tips to help parents and caregivers of children with or at risk for a developmental delay or disability. You don't need to fill out every part of the workbook. This is to guide your thinking and actions, so use what is helpful to you.

Defining Terms

What is Advocacy?

Advocacy is standing up for the rights, needs, and interests of yourself (self-advocacy) or others, such as your child. Parents advocate for their children all the time.

What is Self-Care?

Self-care is taking care of yourself before taking care of others, based on what you know, or information available to you. As the Oxygen Mask Rule goes, you are instructed to put your own oxygen mask on before aiding those who need your help.

What is Peer Support?

Peer support is getting help from a person you know and trust, such as a family member or friend, who has similar experiences.

Part 1: Advocacy

Identifying Barriers

Barriers to Accessing Resources and Services

You may experience barriers to getting support for your child. Circle the barriers you have experienced in the list below. Share with your child's service providers so you can problem solve with them and make sure you get support for your child.

Scheduling

- Trouble making an appointment that doesn't conflict with work or family responsibilities.
- 2. There is a long wait for an appointment.

Language, Culture and Respect

- 3. Staff don't speak the same language that you do.
- 4. Staff don't understand or respect your culture.
- 5. Staff don't understand or respect your religious beliefs.
- 6. Service is not welcoming.
- 7. Providers are not trustworthy.
- 8. Staff/providers don't listen to or respect you and your family's needs.

Navigation Knowledge

- 9. You don't know where to go for help when you have questions or concerns about services.
- 10. Not knowing where to go/what to do when you arrive at the appointment.

Other

- 11. No adequate transportation to the service.
- 12. Trouble finding childcare or a babysitter.
- 13. Worried that you will have to pay more for services than you can afford.

Use this space to brainstorm potential solutions to existing barriers for you and your child.

Barrier	Potential Solution(s)

Communicating Needs

Tips on Advocating for Your Child

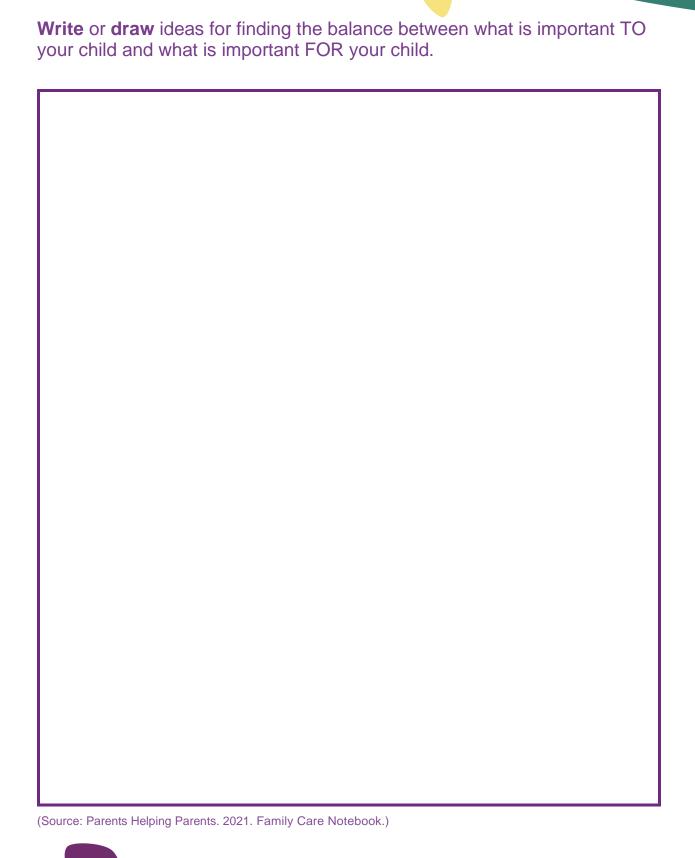
- Get to know the people who can provide support in your child's life (e.g., educators).
- · Keep records.
- · Gather information.
- · Communicate effectively.
- Know your child's strengths and interests, share them with others in their life.
- Explore options.
- Focus on the big picture.
- Involve your child in decision making as early as you can.

(Source: Parents Helping Parents. 2021. Family Care Notebook.)

Important To / Important For

Write down what is important **to** your child, and what is important **for** your child. You can use this form to help visualize your own balance between acting in your child's best interests while supporting their hobbies, likes and dislikes, etc.





Preparing to Advocate

School/Childcare

- Review paperwork from the school or childcare. There may be a record of changes made to support your child or identified needs.
- Ask the school/childcare for ideas and advice. Often, they will have ideas from past work with students.
- Building relationships can take time. Patience and good communication strategies are key. It also depends on the culture of the school (e.g., how willing they are to work with families and other providers).

Providers and Other Professionals

- If you have a doctor, specialist, or therapist who works with your child, you can ask them for ideas and advice. They can also provide reports or suggestions to share with other providers and the school/childcare to back you up.
- Ask for reports that you can give to those caring for your child. These should be easy to read and have practical suggestions.
- Ask them: 'What does success look like for my child?' What can I, my child's school/childcare, or other providers do to support this?
- Think of ideas used by professionals that could work in other settings.
 What works in therapy? What works at home?

Advocacy or Family Centers

Connect with advocacy organizations and family resource centers. They
may run events where you can ask questions, and you may meet people
with similar experiences.

- Find groups and organizations. These can be disability-specific or not.
 They often have free resources that you can use.
- Find websites that promote the voice of children and students. They should use good evidence and value inclusion.

Other Parents and Caregivers

- Reach out to your local community to find like-minded families. They
 may have similar experiences that they can share.
- Develop a network of people to go through options with (e.g., family and friends). Gather thoughts from people who care about your child.

Social Media

- Find social media groups for people like you.
- You can learn from others about their adjustments. They may also have helpful tips on advocating for your child.
- Make sure that they promote evidence-based ideas. There is a lot of misinformation out there.
- Also make sure their values align with yours (e.g., about valuing your child's strengths and interests).

(Source: Australian Government, Department of Education. 2022. Advocacy With and For Your Child: Primary School).

Get Ready to Meet

It is a good idea to prepare for any meetings about your child. Use the table below to help plan.

Before your meeting think about:	Notes:
Who am I meeting with?	
What is the meeting about?	
What do I want to get out of the meeting?	

Before your meeting think about:	Notes:
What do I need to bring to this meeting?	
What paperwork or medical evidence do I need?	
How can I involve my child in this meeting?	

(Source: Australian Government, Department of Education. 2022. Advocacy With and For Your Child: Primary School).__

Goal Setting

It's easier to advocate for your child if you've already taken the time to think through what's important and what your own goals are for your child (and why).

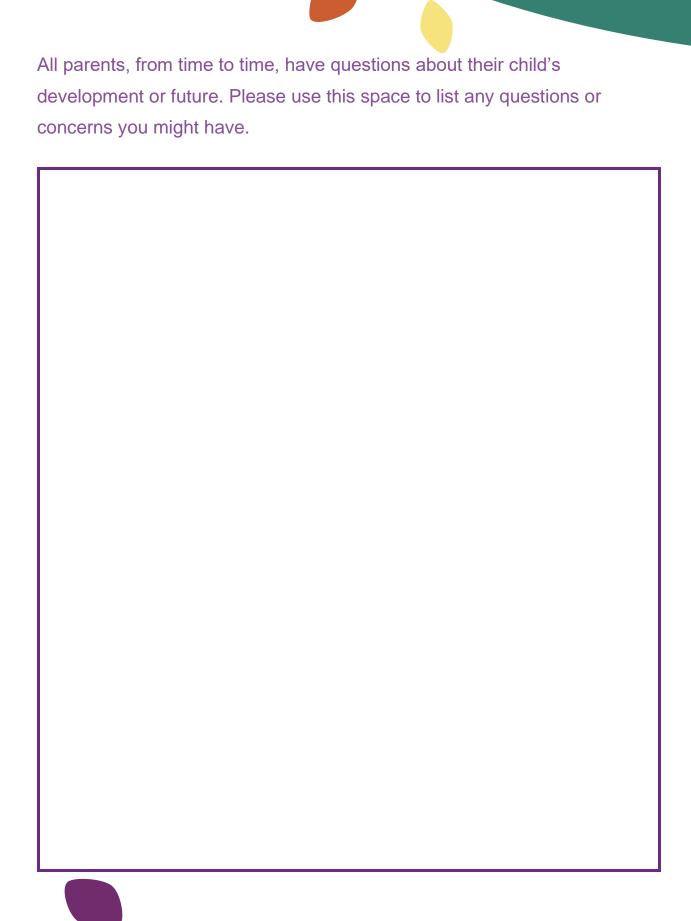
Goal Setting for Your Child

Creating realistic goals for yourself and your child involves ongoing talks with family and possibly others caring for your child. Here are some suggested questions to ask before setting goals for your child:

What is your child's favorite part of the day?

What do they enjoy learning about? What interests them?

What do you look forward to? What do they dream about for the future?



Goal Setting Tactics

There isn't one right way to set goals. These are just a few tips and strategies for goal setting that can be adjusted. It may help to start off with a general idea of what you are looking to achieve.

As a parent/caregiver, you're trying to set goals in everything you do, but time is not always on your side. This section gives you space to write down what you want to achieve.

Basic steps for setting a goal for your child:

- 1. Ask yourself what you would like to see happen for your child (could be in school/childcare, socially, etc.). Why do you want it to happen?
- 2. Ask others what they want for your child. (If they are old enough, support your child in answering by asking them follow-up questions or by having them draw out ideas.)
- 3. Write down your and others shared goal(s) in a notebook or anywhere you can easily refer back to.

(Source: Australian Government, Department of Education. 2022. Advocacy With and For Your Child: Primary School.)

Another tactic for effective goal setting for yourself and your child is **SMART**, which is an acronym used to map out a goal in a clear format. It stands for Specific, Measurable, Achievable, Relevant, and Time-Bound. Having each of these steps in mind can help you lay out what is needed to achieve the goal. This could be a good communication tool to share with your child's service provider.

Step 1: Specific

What do you want to accomplish?

Step 2: Measurable

What do you need to do to reach the goal?

Step 3: Achievable

Is the goal realistic?

Step 4: Relevant

Why do you want to achieve this goal?

Step 5: Time-Bound

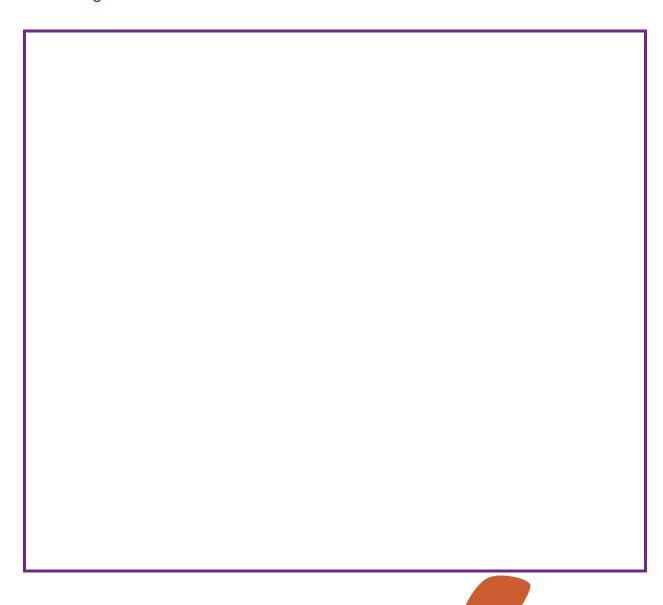
When do you want to reach this goal?

(Source: Doran, G. T. 1981. There's a SMART Way to Write Management Goals and Objectives. Journal of Management Review, 70, 35-36.)



Example Goals:

- For my child to feel comfortable playing with other kids their age
- For my child to understand and follow rules at their childcare/school location
- For my child to be able to communicate to me in words how they are feeling



Advocating for Yourself

To effectively advocate for your child, it is helpful to be aware of your own strengths and challenges. Knowing yourself and advocating for your own needs helps you as well as your child.

Below are a few tips on self-advocacy:

- Take the time to understand your personal needs (i.e., what makes you feel most comfortable, healthy, etc.).
- Prioritize your needs.
- Know what kind of external support you feel most comfortable with.
- Ask for help when you need it.
- Be assertive.
- Communicate directly, but respectfully.

Part 2: Self-Care

Taking Care of Yourself

Taking care of your own mental and physical health is important not only for you, but for your child. Below are some ideas for things you can do to care for yourself depending on how much time you have.

By Time Amount

When you have one minute...

- Stand up and stretch
- Drink a glass of water
- Listen to a song you love
- Wash your face
- Lie on the floor
- Just zone out

When you have 30 minutes...

- Go on a short walk
- Take a shower
- Have a cup of tea/coffee
- Listen to a podcast/music
- Text/email a friend
- Eat a snack

When you have an hour...

- Take a nap
- Do your favorite exercise
- Draw or color something
- Write down how you feel/what you want to get done that week
- Read

When you have a day...

- Spend time with a friend
- Watch a movie
- Make yourself a meal
- Do nothing! Don't pressure yourself to do a self-care activity if you don't have the energy

By Type

Mental

- Hobbies
- Setting Boundaries
- Limiting Screen Time
- Reading for Fun
- Meditation/Mindfulness
- Talking to Someone

Physical

- Exercise
- Sleeping
- Healthy Eating
- Drinking Water
- Personal Hygiene
- Regular Check-Ups with Doctor
- Movement and Stretching

Emotional

- Journaling
- Social Connections
- Community/Peer Support
- Self-Compassion
- Self-Reflection
- Affirmations

Spiritual

- Connecting with Nature
- Prayer
- Rituals & Ceremonies
- Acts of Service
- Gratitude Practice

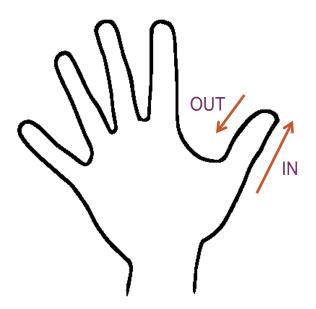
Check-in Reflection

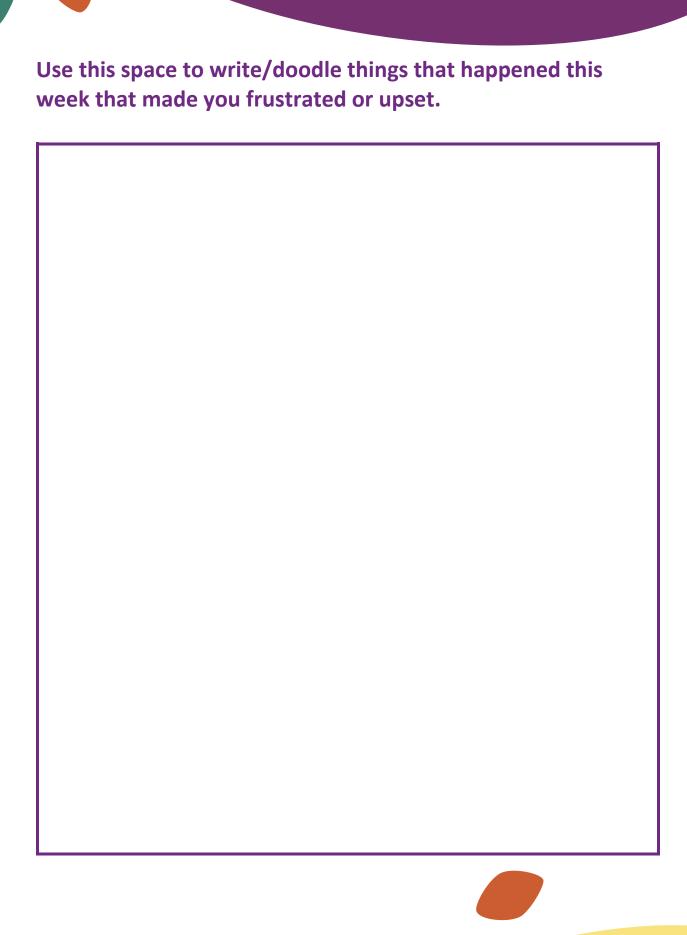
What was the best thing that happened this week?
What happened this week that I am grateful for?
How did I make time for myself this week?
What was my overall mood like this week?
How did I show kindness this week?
What did I do to take care of myself this week?
What do I want to change next week?

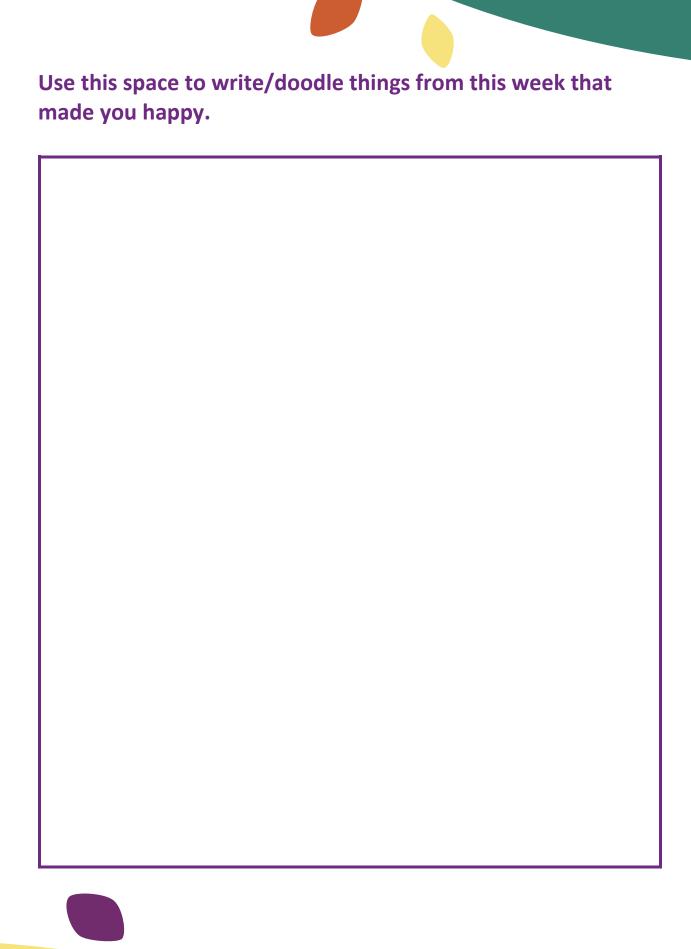
Five-Finger Breathing

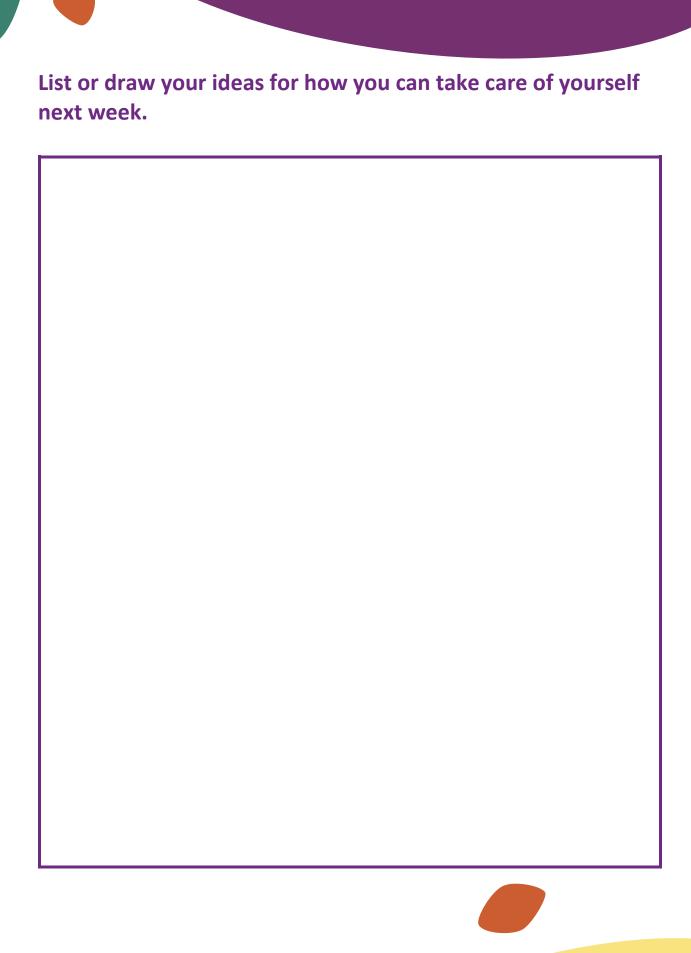
Five-finger breathing is a simple but powerful breathing technique that helps with relaxation that you can do just about anywhere.

- 1. Hold one hand out so that it has space between your fingers.
- 2. Use the index finger from your other hand.
- 3. Bring your index finger to your hand while holding out where your thumb meets your wrist. As you move your tracing finger up to the tip of the thumb, take a slow breath in.
- 4. When you reach the top of your thumb, slowly breathe out as you trace down the other side of your thumb.
- 5. Repeat for all fingers until you have traced your whole hand.











Peer Support

Caring for a child with developmental delays or disabilities can sometimes feel overwhelming or isolating, but you are not alone. Connecting with other parents navigating similar situations and challenges can be helpful for both you and your child. Here are some places that you can turn to for support:

- Family Resource Centers provide support for families of infants and toddlers
 from birth through age 2. The people who work there understand the concerns
 and challenges parents and caregivers face when searching for services and
 information, and many are parents of children with disabilities themselves. Find
 a Family Resource Center near you with this interactive map:
 https://admin.publichealth.lacounty.gov/mch/helpmegrow/es/service-locator.html.
- Family Empowerment Centers are parent-led organizations that provide training, information, and advocacy support to families regarding special education for children ages 3 through 21. Find a Family Empowerment Center through Seeds of Partnership: https://www.seedsofpartnership.org/fec/index.cfm | (916) 228-2388
- Family Voices is a national network of families of children and youth with special healthcare needs and disabilities that promotes partnership with families to improve healthcare services and policies for children. Learn more at https://familyvoices.org/ | (781) 674-7224
- Parent to Parent-USA programs provide emotional and informational support
 to families of children who have special needs, most notably by matching
 parents seeking support with an experienced, trained 'Support Parent'. Learn
 more at https://www.p2pusa.org/.

Additional Resources

- Help Me Grow LA Resources | <u>http://publichealth.lacounty.gov/mch/helpmegrow/resources.html</u> | (833) 903-3972
- First 5 LA | https://www.first5la.org/ | (213) 482-5920
- Advocating With and For Your Child: Primary School (Australian Government, Department of Education) | https://www.education.gov.au/disability-standards-education-2005/students/english/advocating
- Parents Helping Parents, Family Care Notebook | https://www.php.com/the-family-care-notebook/
- LAUSD Student and Family Wellness Hotline provides support with mental health, immunizations, health insurance, food, housing, and more; support for LAUSD students but no one is turned away: (213) 241-3840





Let's Talk About Your Child's Development!

Track your child's development and connect to **free** and **low-cost** services, resources and support in Los Angeles County.

WE CAN HELP WITH:

- ✓ Referrals to developmental screenings and check-ups
- Connections to organizations that provide services for developmental delays
- ✓ Growth milestone tools
- Support for families

We are here for you! Call 833-903-3972 or visit HelpMeGrowLA.org





