



# WORKBOOK

## BACK TO SCHOOL ADVOCACY WORKSHOP FOR PARENTS OF NEURODIVERGENT LEARNERS

JOURNEYS  
*with* PDA



[JourneysWithPDA.com](http://JourneysWithPDA.com)





# CHILD PROFILE



Date:

# First Last Name

## Parents Names

☎ 123-456-7890

✉ hello@reallygreatsite.com

## Diagnoses

- Autism Spectrum Disorder with Pathological Demand Avoidance profile (PDA)
- General Anxiety Disorder
- ADHD
- Specific Learning Disorder: Math, Reading & Handwriting

## Supports

- IEP
- 504
- Use of audiobooks and voice to text
- Additional transition time
- Scheduled breaks
- Organizational bins in classroom
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## Positive Attributes

Child is highly social. S/he loves to spend time with friends. S/he especially loves to play (minecraft/soccar/ect.) with others. S/he enjoys (hobby/art/drawing/ and is always excited to share this and teach it to others. S/he is great with younger children. S/he is a great helper and loves working on projects alongside others. S/he is funny and loves to make others laugh. S/he also enjoys music and singing.

## Challenges

- Expressing her/his need for help
- Reading and writing
- Working in groups larger than 4
- Transitioning from one topic to another
- Staying focused in busy work environment
- Keeping her/himself organized
- Following direct commands
- Highly sensitive to negative tone & body language
- Unexpected changes to schedule or routine
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## Special Interests & Hobbies

- Art, drawing & painting
- Loves animals, especially cats
- Playing Roblox with friends
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# FIRST LAST NAME



**FIRST GRADE**

**Firstname is autistic with a PDA profile. They experience very high anxiety that is constant and present in every aspect of their life. They are very bright and creative. They are very social and love to be around their friends. They love to help others. They enjoy music and hands on activities that allow for movement.**

## STRENGTHS

- Very social
- Enjoys helping others
- Creative and enjoys art
- Works well independently or in small groups
- Great with technology
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## INTRESTS- HOBBIES

- My pets
- Roblox
- Minecraft
- Music
- Roller skating

## PARENT CONTACT

- ☎ 123-456-7890
- ✉ hello@reallygreatsite.com
- 📍 123 Anywhere St., Any City

## HELPFUL SUPPORTS

- Declarative language
- additional time for transitions
- autonomy in decisions
- autonomy in schedule
- breaks to allow for self-regulation
- use of audio books
- use of voice to text
- and other supports outlined in IEP

## AREAS NEEDING SUPPORT

- Organization
- Reading
- self regulation
- staying focused
- handwriting
- communicating needs
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JourneysWithPDA.com

**Pathological Demand Avoidance profile resources: [journeyswithpda.com](https://www.journeyswithpda.com) and also [pdasociety.org.uk](https://www.pdasociety.org.uk)**

# MY IEP ACCOMMODATIONS

My Teachers who know I get these Accommodations:

- Mrs. Wilson
- Mr. Wolfe
- Carl (janitor)

During Testing:

- Gum
- Audiobooks
- Breaks anytime
- Snack when needed
- Take as long as I need
- Verbal tests

My SAFE PERSON is:

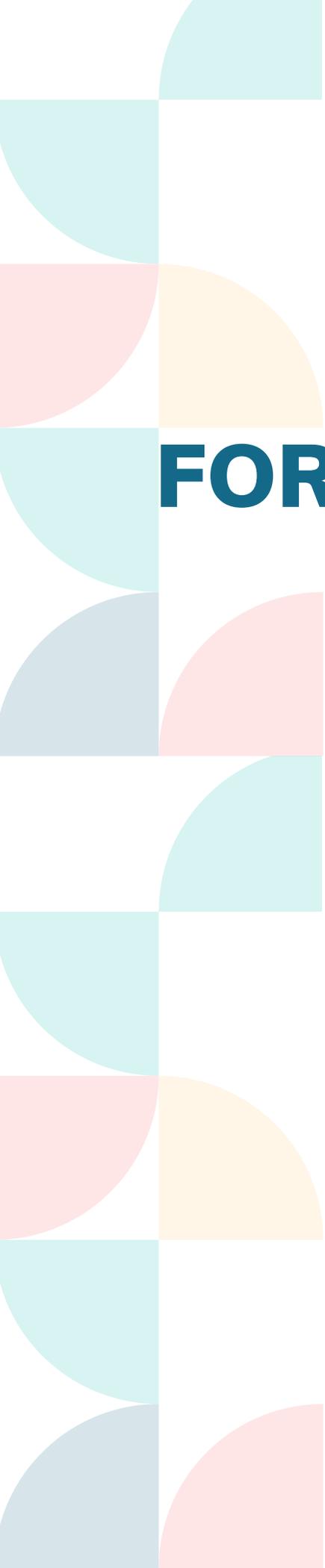
Mrs. Wilson

I can talk to her any time by giving my teacher a break card and going to Mrs. Wilson's room. If she's busy, I will get an iPod and turn on an audiobook until she can talk with me.

## My Accommodations to make school more accessible:

- See Mrs. Wilson, any time I need a break.
- Taking breaks anytime my brain can't think any more.
- Check-in with Mrs. Wilson at the beginning of the day, so I know what is happening that day. I can tell her any concerns I have and she'll help me advocate and organize my brain.
- A basket in class to keep all of my stuff in for that class. Each teacher will help me remember to put all my stuff back at the end of each class.
- No Homework unless I feel up for working on something.
- Audiobooks in the library, instead of recess.
- Chewing gum is ok.
- Checking in with mom via text when Mrs. Wilson isn't able to help.
- Staying home when I need a low demand day.
- If I'm having a BAD day, I can spend the day in Mrs. Wilson's room. It's ok to have a bad day and still come to my safe place. There will be no demands today.





# FORM LETTERS



## SAMPLE LETTER REQUESTING EVALUATION FOR SPECIAL EDUCATION

Today's Date (include month, day, and year)

Name of Principal or Special Education Administrator

Name of School

Street Address

City, State, Zip Code

Dear (Principal's or Special Education Administrator's name),

I am writing to request that my son/daughter, (child's name), be evaluated for special education services. I am concerned that (child's name) is not doing well in school and believe he/she may need special services in order to fully access their education.

Specifically, I am worried because (child's name) does/does not (give a few direct examples of your child's problems at school).

We have tried the following to help (child's name). (If you or the school have done anything extra to help your child, briefly state it here).

This letter serves as my request and consent for an evaluation of my child. Please provide me the contact information of the person who will be coordinating the evaluation.

(Child's name) has been diagnosed with ... by ...

I can provide you with the evaluation report.

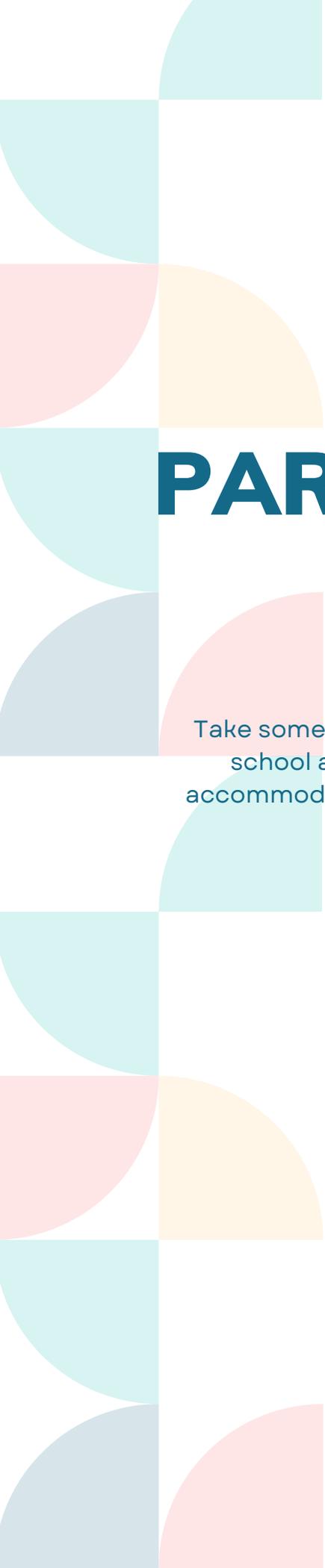
Thank you for your prompt attention to my request. I look forward to your response.

Sincerely,

Your name

Contact info.





# PARENT IEP INPUT & CONCERS

Take some time to think over what your goals or expectations are for school and the things that you feel will be helpful supports and accommodations. Have it all listed and written out prior to the meeting.



# My IEP Goals & Input

My Child's Name: IEP Meeting date of meeting 2022

Positive description, attributes and important info:

- MyChild is smart, creative, energetic, kind, caring, highly social and driven. She loves to help others. Especially younger kids. She loves art, music and movement.
- MyChild is a “master masker”. Autistic masking is a social survival strategy used to “fit in” and “blend in” with peers. MyChild is pretending to be calm, happy and ok. Masking also stops MyChild from asking for help or voicing her true feelings. Masking takes an extreme amount of energy. Prolonged masking can cause mental and emotional damage, meltdowns, blowups and shutdowns.
- MyChild is autistic with extreme anxiety that interferes with daily tasks. This anxiety often causes MyChild to seek control over their environment. This also causes them to avoid tasks that are challenging but also ones that are fun or desired. This is know as Pathological Demand Avoidance profile of autism. PDA for short.

My Main Goals & Focus:

- For school and learning to be accessible for MyChild while maintaining positive mental health and keeping anxiety and avoidance to a minimum.
- For MyChild to be able to build trust with her teachers and be able to attend school while maintaining a calm and peaceful home life with minimal autistic meltdowns and shutdowns.
  - Build trust (safety) not grit.
  - MyChild needs autonomy especially in her schedule and location.
  - Autonomy= freedom to make decisions and choices. Sense of control over herself.
  - Independent= not depending of others. Isolated. Cast aside. Rejected.
  - MyChild needs to not feel guilt or shame for needing breaks and accommodations.
  - Due to MyChild's ability to mask so well and her PDA, she is not able to advocate for herself.
  - Unless she is in a safe/private place with a person she trust she can not express her feelings, challenges or concerns.
  - Parent should be considered MyChild's advocate and voice.

Diagnosis:

- Autism Spectrum Disorder with demand avoidance profile (Pathological Demand Avoidance)
- Anxiety
- ADHD
- Specific Learning Disorder

Helpful Accommodations:

- Assistive Technology
- Audiobooks & digital text books
- Breaks
- Safe person
- Executive function and organizational support
- flexible attendance





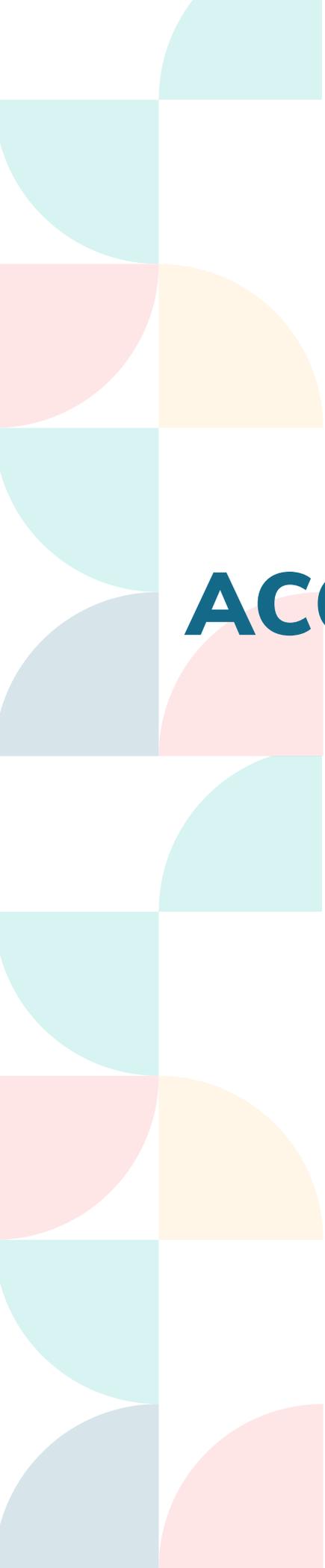
# CANNED RESPONSES



# CANNED RESPONSES AND STATEMENTS TO USE DURING THE IEP PROCESS.

- Tell me more about...
- I'm curious, can you explain that to me?
- Please send me the policy that shows that this is how that need to be handled?
- Help me understand...
- I need some time to process that. Can we come back to that later?
- Based on PDA, help me understand why that is what's best for my child.
- (in an email) Per our conversation on (Add date), then list what was discussed. Everything should be in writing, so if you have a conversation, follow it up with an email.
- Help me understand your perspective.
- I do not agree with that.....it makes my skin crawl (Kerissa actually said this in an IEP meeting)





# **SUGGESTED ACCOMMODATIONS**



This is a list of accommodations that have been found to be support to PDA students. This is not a one size fits all list. Some of these might not be suitable for your child. Some of these recommendations might not be available in your school or state.

- Flexible or adjusted schedule, shortened school day
- Delayed/flexible start - 9:30ish to 2:30. (Sometimes he doesn't make it in until after lunch.)
- Guidance counselor or safe person meets him at the door
- Safe person who can co-regulate and problem solve. Help with separation anxiety
- Safe person check-in at start of day, mid-day or at the end of the day. Check-in can be for a time to go over assignment expectations, projects, organizational help or resolving social frustrations
- No homework. No makeup work if he misses school, or doesn't finish at school
- Graded on work completed
- Shortened assignments to prove mastery
- Small group instruction with the special Ed teacher a few times a week
- He can skip specials if he wants (music, art, Spanish, etc)
- Access to noise canceling earbuds throughout the day
- Access to resource room and teacher
- Scheduled quiet time/breaks in the resource room (scheduled after a subject/class that is dysregulating or challenging
- Can request breaks as needed to allow time and space to self regulate
- Break cards or another non-verbal way to communicate needing a break
- Can't be expected to remember things on his own (need to bring valentines, don't forget to wear your school shirt tomorrow, etc.)
- Flexibility on how work is accomplished: takes test verbally, shortened assignment, typed or voice to text instead or writing, can use word bank or multiple choice
- Quiet room or space available for self regulation
- Alternative option for lunch (away from the big crowd)
- "Resource room" can still be overwhelming even though it is thought of as a safe space by everyone else.
- Alternative safe space where there are no other students, it's quiet, calm and no distractions. Library, office, conference room, closet. The child can sign into class on Zoom so he doesn't have to be in the chaos of the classroom.
- Involve child in special projects where they can have a leadership position and help others. (Helps the custodian with projects like putting desks together, vacuuming, organizing lost and found, helping in a lower grade classroom)
- Color code their things: math book gets a blue cover, math notebook is blue etc. Then color code a schedule. Hour 1 green, Hour 2 Blue, Hour 3 red. So they are getting a color rather than supplies.
- Student's books and supplies are kept in their classroom so they just had to get themselves to the classroom.
- Executive Functioning support- THIS IS MORE THAN JUST ORGANIZATION! This includes working memory, flexible thinking, self control, schedule and time management. (When I asked for this the team automatically just wrote in an organization goal. Seth Perler is great resource on this. Tilt Parenting has some valuable podcasts with him on supporting this. As does the Neurodiversity Podcast.)
- Address the amount of time he has to transition through his IEP
- Involved child in decision making (Ross Greene CPS)
- Flexibility in the school and the adults. The environment (people/spaces) have to be flexible NOT the child.
- Optional recess - the chaos and social pressure might be difficult and overwhelming. A quiet break to unwind might be a more supportive option, (Sit in library read/listen to a book)
- Identify what calms the child's brain and gently work those things in whenever possible. Fidget toys, wobble chair, putty, slime, take a walk. (Another mom talked about that when her son did 10 math problems he got to take a scooter ride. This is an excellent way to support the nervous system regulating.



## Continued list of accommodations.

- Parents being allowed to determine if their child is able to attend school that day based on their anxiety level and mental health
- No social skills training. (Most school systems only know how to 'train' autistic kids in neurotypical social skills. It creates a huge demand. The school needs to provide space for our kids to be with other autistic kids and/or gifted if that applies for your child. We want to encourage our kids to be authentic and true to themselves.)
- Sensory support (request to have the school OT involved)- chewing gum, listening to audiobooks or podcasts when needed and during testing, breaks, riding an exercise bike, taking a walk instead of PE, ear plugs/noise canceling headphones, wobble seat, fidget toys, slime
- No stopped or hindered from stimming (drawing on skin, hand flapping, jumping, humming, tapping, lip picking, ect.)
- Flexibility, autonomy, choices, collaboration, declarative language, calm tone of voice & body language
- Rewards and threat of consequences/punishments create a demand and will cause Jaden to further avoid or shut down. There is no reward or punishment that will alter her behavior. Flexibility, trust and collaborative problem solving is the way to alter her behavior
- PANDA (PDA Society) Pick your battles, Anxiety Management, Negotiation/Collaboration, Disguise & manage demands, Adaptation
- Test support: option to take the test separately in a quiet space, assistance reading the test and writing answers, additional time, verbal testing to check for comprehension
- Allowed to contact parent and request to go home- crisis plan for BAD days
- Curriculum designed to foster nervous system regulation
- Does not have to attend if there is a substitute. Or has the option to be with her safe person
- Curriculum to engage gifted brain. Not more work, deeper thinking and incorporate special interests
- Snacks as needed
- Crisis plan when they hit a period of burnout (very common for autistic brains) there was already a plan in place so more stress wasn't added over the amount of school work piling up
- Access to curriculum through audio/digital format
- A concrete, clear plan, showing what the IEP supports are written with low demand language for the student
- PDA training for all staff and not just teachers
- Focus on connection and flexibility over compliance
- A top priority (goal) is mental, social and emotional wellbeing. School does not cause meltdowns and distress at home. Home is for resting and self-regulation. It is a calm, safe place with very low demands. Attending school requires a large amount of energy and masking. They need time to rebuild her energy and mental capacity. The peace, safety and mental wellbeing of the entire family will not be jeopardized for homework, attendance, ect.

**Important tip:** Something that was beneficial for us was reframing the wording in our brain to "making school accessible". Your child might 'appear' to be fine but you are seeing the results at home. If your child has to mask, then school as it is currently set up is NOT accessible to them in an authentic way. They deserve space to be their authentic self. The demands of keeping up will be more than they are able to mask. This just naturally increases with age. They were more able to mask in k-1st than in 2nd and 3rd. We need to continue to make sure that school is accessible for them.

