

Shutdowns and Stress in Autism

Articles

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Part 1: Can shutdowns hurt your child?

What is a shutdown?

A shutdown is a particular sequence of behavior which we observed in a child diagnosed as high-functioning within the autistic spectrum.

In academic settings when pressured by an adult to perform tasks that were difficult, she became unresponsive, sleepy, immobile, and limp to the touch for several minutes, and then fell asleep in a chair for as briefly as 10 min. and up to 2 hours. These “shutdown” (SD) states were always triggered by social stress of a certain kind and they became more severe and frequent over a period of about a year.

Do shutdowns worsen the symptoms of autism?

During this time the child had entered a mainstream kindergarten class after spending her preschool years in a special education classroom. Soon after entering kindergarten she developed fears of the bathroom which interfered with normal toileting and bathing, she woke in fear several times during the night and was afraid to sleep in her bed. She would only wear clothes of a certain type and color, became socially withdrawn, highly emotional, and had difficulty remembering previously mastered academics. Her drawings became illegible blobs and she colored in large strokes ignoring the lines. She also began exhibiting refusal behavior at school and in speech therapy. While at school she spent all of her recess time on the swing and she craved that activity at home as well.

The child’s behavior became so extreme that she was removed from school and was home schooled for several months. It was during home school sessions that we recognized the pattern of shutdowns and realized that she was probably having them at school.

We began a project to understand what was causing the shutdowns and whether they could account for the behavior changes we observed. We also wanted to find a way return the child to school and avoid future shutdowns.

By eliminating shutdowns using the strategies discussed in part 2 of this article, the SD child has overcome most of her fears, she sleeps in her bed through the night, wears a variety of clothes, and has become more socially engaged and animated. Eye contact has improved. She draws legible pictures and colors within the lines. She has also improved in academics and rarely exhibits refusal behavior. When faced with difficulty she asks for and accepts help. She has returned to a special education classroom and continues to improve.

This work is based upon our observations of this 6 year old girl we call the “SD child”, but the notions discussed have broader applicability.

Medical professionals are invited to read the scientific version of this paper entitled, “Shutdown States and Stress Instability in Autism” which contains a more complete picture of the physiology and scientific concepts [22].

This parent version was written to convey important information to parents about this syndrome, how it may impact their children, and to provide suggestions for managing a child prone to these episodes.

Shutdowns and stress

We observed a predictable sequence of behavior whenever the SD child was pressed to complete a difficult task. We call this progression a “stress reaction”. If pressed too far, the stress reaction would escalate into a shutdown (See fig.1).

When presented with a difficult task, the child looked away from the work area and became distracted with objects around her. She also did this after being corrected for a mistake, such as making a letter incorrectly. When she was directed back to the task, she had difficulty looking at the page, she kept looking away. She rubbed her eyes and kept them closed. We identified eye rubbing as the threshold stress reaction in the SD child. Once she rubbed her eyes, shutdown was inevitable if the adult continued to press her. When again redirected, she became less verbally responsive and kept her eyes closed.

Fig.1. Progression of stress response to shutdown In order to test if the child was attempting to “escape” the task, an enticing toy was offered for finishing the task. She would show great interest and return to the task but seemed disoriented, did not know what the task was, and could not continue. She wanted the toy reward, but seemed incapable of finishing the task.

If pressed further, the pencil would fall from her hand, she would slump into the chair and say she needed to sleep. If reminded again of the reward she would say, “I have to sleep”. Attempts to rouse her by touch had no effect. Her hand went limp to the touch and she would not respond. She remained conscious, but would be extremely reluctant to respond. She would then fall asleep in the chair. She would sleep for as little as 10 min, up to 2 hours. When she awoke, she would complete the task, but she was more prone to shutdowns for the rest of the session. A detailed description of the academic setting in which these events occurred is in APPENDIX I.

If shutdowns occurred on 3 consecutive days, the child seemed prone to them for up to 3 weeks.

Stress reactions have also been observed in non-academic settings such as: meeting strangers, greeting friends and family during home visits, participating in play-dates with several other children, conversations with adults when the child was asked to recall what she did or what she liked about a recent event, and play sessions in which a sibling pressed the SD child to participate in particular play themes. In these circumstances the child was not pressed to respond once she demonstrated reluctance, and this may be why the stress response did not escalate into a shutdown.

Are shutdowns actually avoidance behavior?

One can not be sure exactly where to draw the line between intentional and involuntary acts, but we believe shutdowns were driven more by physiology than by learning for several reasons:

First, we have seen the SD child exhibit frank refusal behavior by folding her arms across her chest, turning her back to the teacher and declaring that she was angry and would not do the task. This behavior is along the same lines as the avoidance behavior described in the literature, which is often disruptive, violent or destructive [2,3,4]. In contrast, shutdowns are more accurately characterized by extreme passivity.

Second, the SD child exhibited limpness followed by sleep which was real and not feigned. It is difficult to imagine a child could sleep at will under these circumstances.

Finally, we found no enticement could compel the SD child to continue working on the task. She was highly motivated to earn the particular toys that were offered for finishing the task. She tried to finish

but could not. The need to rest was apparently greater than the desire for the toy. These observations lead us to believe that shutdowns were not adequately explained as learned avoidance behavior.

What causes shutdowns?

Triggers

We suggest that shutdowns occur when an abnormal stress response is triggered by a particular set of circumstances. We will first discuss the events which seem to trigger the abnormal stress response.

In the SD child, the stress response was most easily triggered when an adult pressured the child to respond verbally to a question which she found difficult.

An ongoing social pressure to respond was the first element that triggered a stress response. We only observed shutdowns when another person was interacting directly with the child. We never observed shutdowns when the child played alone, interacted with animals, machines, objects or played challenging computer games.

It is likely that many autistic children have a social phobia which is evidenced by their difficulties with eye contact and their reluctance to engage socially. Indeed, an abnormal stress response to social encounters probably operates in those suffering from social anxiety disorders, as well as autistics.

We believe that the child was aware that her difficulty responding would cause an unwanted reaction in others. She may be asked to repeat or to clarify the answer, the adult may express displeasure in a subtle way, or she may be told she has given an incorrect response. The SD child expressed a strong desire to be “a good girl” and having difficulty answering was not something, in her mind, that a good girl would do.

Certain tasks were especially difficult for the SD child to perform. We found that the tasks fell into a hierarchy of difficulty consistent with the work of Volkmar & Cohen [1] in which tasks requiring a verbal response to a verbal question elicited the quickest stress response (e.g., “What rhymes with hat?”). The more concrete and visual the problem became, the less stressful it appeared to be for the child. This pattern is what we would expect from a child with language difficulties.

We call this combination of social and performance elements a “social performance expectation”, and in the SD child, this is what triggers the stress response. If pressed enough, the stress response will escalate into a shutdown.

The abnormal stress response

A normal child has a stable reaction to stress. We suggest that shutdowns are caused by an abnormal, unstable response to stress, which we call a “stress instability”, illustrated in Fig.2.

In certain settings, the social performance expectation discussed above brings on a mental dullness that blunts social performance. The resulting increase of stress then causes a deepening of the dullness and a further slippage of social performance. This vicious circle of increasing stress and further deterioration of social performance plays a role in shyness, introversion and possibly social phobia. In children, this escalating cycle can lead to the shutdown episodes we have described. Repeated shutdowns over time can cause nervous system damage and developmental impairments within the autistic spectrum.

The stress instability causes the magnitude of the body’s stress response to far exceed that which is normal. If severe enough, the child will shutdown so that her body can recover. The levels of stress hormone are higher than normal and they remain elevated for a prolonged period, both of which causes damage to the child’s brain.

The stress instability is exquisitely sensitive and can be set into motion by the slightest social impairment or development delay. The magnitude of the instability depends on the child's sensitivity to social stress and the reactivity of stress-processing neural circuits. Initially, these aspects of the nervous system depend on genetic and environmental factors such as prenatal exposure to hormones and other substances circulating in the mother's blood.

How shutdowns can impair a child

In the developing child, stress instability severe enough to cause shutdowns can also cause pathological changes in the brain and developmental delays. The resulting symptoms include emotionality, fearfulness and anxiety, social withdrawal, learning disabilities, language difficulties, as well as rhythmic motor activity. The following is a brief description of the physiology we suspect is involved in the instability and also a discussion of mechanisms whereby the pathological changes and development impairment come about.

Lingering emotionality, fearfulness and social withdrawal

The basolateral amygdala (BLA) is a part of the brain which plays a large role in emotions. It can become hyperreactive if exposed for several days to excessive levels of the stress-mediating neurotransmitter, corticotropin releasing factor (CRF). Once hyperreactive, the BLA stays that way for several weeks [5].

We could expect a child with an hyperreactive BLA to be overly emotional, easily frightened, and/or socially withdrawn for several weeks after a stressful event or shutdown. Indeed, shutdowns seemed to make the SD child more susceptible to additional shutdowns for several days. Repeated shutdowns on consecutive days raised her susceptibility for up to three weeks.

Thus we can see that a child that has had a difficult week at school may have a hard time coping in the weeks to come. This may also explain the ups and downs seen in autistic children which seem to last weeks at a time.

What is important is that the hyperreactivity of the BLA may be reversed by avoiding excessive stress over time. If a child prone to shutdowns at school can be taught using low-stress methods, he will function better and continue to improve. Unfortunately, most educational programs for autistic children focus on "working through" stressful situations rather than reducing them. Low-stress teaching approaches which have been effective with the SD child are discussed in part 2.

Stress-levels of the hormone cortisol enhance the creation of emotional memories in the BLA [25]. A child under stress will remember emotional, stressful, events better than non-stressful ones. He will recall the unpleasant physical sensations, his difficulty responding to others, and how others reacted to him, better than he will remember other events. Painful memories increase the child's anxiety prior to the encounter, and also his stress during the encounter. This stress-driven mechanism then causes an even deeper deterioration in performance. Thus we see a vicious circle leading from one stressful social event to the next.

Learning disabilities

Sustained high levels of stress hormones called glucocorticoids can impair verbal memory [6,8,9,10,11] and learning [12] by damaging the part of the brain known as the hippocampus (H) [8,11]. This impairment of verbal memory may contribute to the language deficits seen in autistic children. In Kindergarten and early grade school, memorization difficulties might be seen as a learning disability.

Hippocampal damage also impairs social function, thereby contributing to stress and hence to further degradation of social function above and beyond the effects of stress on the BLA. Thus, there exists another vicious circle spanning a time that is long enough for the hippocampal damage to develop.

Language difficulties

Stress also affects the ability of the prefrontal cortex (PFC) to modulate the cognitive processing of sensory input from social interactions. This means that the child's ability to process what he sees and hears is impaired.

The cumulative effect of stress on the BLA, hippocampus, and the prefrontal cortex selectively impacts language because the most stressful events are those in which the child is expected to "perform" using language (See fig.3).

The SD child's ability to sort out what has been said and to derive meaning from it is impaired. Her ability to remember verbal information is impaired, and she has particularly strong, unpleasant emotional memories of her past difficulties. The circumstances which cause her the greatest stress are all tied to language.

Rhythmic behavior

The SD child demonstrated an increased desire to sit on a swing for long periods of time during the period she was suffering shutdowns. It is known that autistic children tend to engage in more rhythmic motor activity when difficult academic tasks are introduced [7]. This may be because at certain low frequencies, rhythmic sensory stimulation has a calming effect. We see this in mothers who rock their babies, and people who relax in a rocking chair or hammock. A child who rocks or engages in other rhythmic movements is simply trying to calm himself. It is likely that beta endorphin is released during this activity [13].

How common is this syndrome?

It is possible that many autistic children suffer shutdowns that are unrecognized by parents who have not looked for these patterns, and by physicians who have not inquired about them. Shutdowns can easily be misinterpreted as avoidance behavior.

We expect that children prone to "sensory overload" or aggressive outbursts such as yelling, violence, and destruction of property also suffer a stress instability that presents differently based on the temperament of the child.

Our explorations indicate that shutdowns may also be common among autistic adults. Accounts of shutdowns by autistic adults are shown in APPENDIX II.

Shutdowns brought on during social pressure to perform may be common enough to define a subtype in the autistic spectrum.

Part 2. Shutdowns and your child

Signs of hypersensitivity to social stress in infants

Shyness is an early sign of hypersensitivity to social stress which was apparent in the SD child as an infant. Since prosocial behavior develops rapidly in the second year of life, this is the time when intervention may be the most effective [14]. We believe that sensitivity to social stress is a core feature of the stress instability that we have observed in the SD child. Parents of shy infants risk nothing by contacting their county regional center or other agency qualified to screen for developmental delays. If the screening reveals any developmental delays, parents should take their child to a pediatric neurologist skilled at diagnosing autism. This may lead to psychological testing to confirm a diagnosis.

Identifying and controlling triggers

Triggers may vary from child to child but one would expect social situations to be particularly difficult for an autistic child. Environmental factors should also be considered for children with hypersensitivities to light, sounds, smells or tactile sensations. It is equally important to identify when stress reactions do not occur.

If school is particularly difficult for your child, make arrangements to observe him at school. Collaborating with teachers and therapists will help to identify when the child shows stress, what the symptoms are and what seems to help him recover. APPENDIX III describes methods for identifying stress triggers and shutdowns in your child.

Above all, parents must realize that no one else is going to take control and manage this problem for their children. It appears that the medical profession has so far not seen shutdowns as an involuntary state of severe stress. Educators and therapists may assume the behavior is intentional and try to train your child out of it, which will only make matters worse. The only way parents can help their children is to know better than anyone, how their child responds and make sure that he is placed into an environment that allows him to learn and to improve.

What to do if your child has shutdowns

Immediate concerns

If the child is in a crisis such as the one we described in the SD child, the child should be checked by a physician to rule out other causes. If the doctor finds nothing, then removing the main source of stress from the child's life is vital.

Removing the source of stress requires that you know what it is. If school is part of the problem, schedule a meeting with the teacher as soon as possible to discuss the matter.

In general the child needs:

1. The source of stress removed, reduced or modified so he can tolerate it.
2. Preventing shutdowns should be the primary consideration.
3. The child will need a few weeks to allow him to return to a less reactive state. The child should be given plenty of time for activities that soothe him, such as rhythmic movements or "stimming".
4. The child should be exposed to novel, exciting and enjoyable activities that will create positive emotional memories.
5. It may be necessary to temporarily lighten the child's schedule. This can be done by reducing the number of hours the child is in situation that is stressful for him such as school or therapy. It can also mean reducing the duration of academic tasks that are particularly stressful.
6. If it is necessary to continue with stressful activities, they should be made as brief as possible and paired with enjoyable activities. Difficult tasks can be alternated with pleasant, fun activities.

Long term solutions

In the long run, one must find a balance between reducing stress, and participating in activities that are important to the child's development, such as school and therapy.

Many popular interventions are based on the concept of behavior modification which is in essence, rewarding desired behavior so the child repeats it. Although there is proven success with

these approaches in certain cases, a child that is prone to shutdowns may not respond well to this approach. Indeed, it may make things worse.

Autistic writer and artist Donna Williams describes her autism as a severe social phobia , " what I see in approaches to autism is almost always using a kind of control or imprisonment, however pleasant we paint it. Imprisonment of any kind compels us not to stay but to obsess on hiding, avoiding, escaping or complying in order to win reprieve." [21].

Techniques that encourage the child to work through stress will teach him to ignore sensations which are vital for his functioning. With proper training, the child could instead be taught to recognize the signs of stress and to use the tools at his disposal to reduce it. This ability to self-manage is a "pivotal" skill which can produce improvements in wide areas of functioning [16].

The National Autistic Society of the UK has developed an enlightened approach for working with autistics, designated by the acronym "SPELL" (Structure, Positive approaches and expectations, Empathy, Low arousal, Links). The use of "Low Arousal" as a cornerstone of the program is unique among the interventions reviewed [15]. We have not found this approach in American schools. Nonetheless, parents can arrange that their children will benefit from a "Low arousal" atmosphere by knowing their children and assuring that appropriate teaching strategies are used with their child. That is the role of the Individual Education Plan, or IEP.

School placement for a shutdown-prone child

One of the biggest issues facing parents is whether to mainstream their autistic child. Mainstreaming may be ideal for an child that reacts negatively to one-on-one teaching, and is not over-stimulated by an active environment with many other children.

A mainstream classroom may, however, be a poor choice for a child prone to shutdowns for several reasons:

- Unless you have properly advised the staff about your child's shutdowns, what triggers them and how to work around them, your child will probably suffer shutdowns which go unrecognized for what they are. Furthermore, it is possible that shutdowns will be considered "difficult" behavior and treated as such in a mainstream classroom. This will increase the stress in your child and could result in your child refusing to go to school.
- Mainstream classrooms have more children than special education classes, with fewer staff members. Therefore the teacher will have less time to monitor your child, and thus will be less aware of the signs of stress. This may be fine for a child with some self-management skills but it may be difficult to accommodate a child that is just learning to manage stress.
- The speed at which material is presented and the language level of the other children may make your child feel lost, disoriented or embarrassed. All of these feelings only add to his stress and should therefore be avoided.
- The school may offer additional support for your child with a "shadow" aide. The additional attention will be helpful for your child if personalities mesh. You must remember, however, that the aide assigned to your child may have minimal training and little experience with autistic children. If you know all about how your child reacts and how to avoid shutdowns, you may be able to guide an aide to be an effective helper for your child.
- The teacher was most effective with the SD child when she could choose moment to moment, teaching methods that would get the best response from her. Such a strategy may be difficult in a typical classroom since it requires close, constant monitoring and management by the teacher during academic tasks.
- A child coming from a special education classroom should be transitioned into a mainstream class very gradually, starting with a subject the child is particularly good at, and building on positive experiences.

Make low-stress teaching part of the IEP

No matter which intervention approach is used, parents must know whether their child is prone to shutdowns in order to advocate appropriate services for their child. A description of the symptoms and triggers of shutdowns, as well as the importance of avoiding them, should be written into the IEP document. Everyone that works with your child should have a full understanding of what brings on shutdowns, how to prevent them, and how to work around them

The goal of the parents and educators should be first and foremost to minimize the social stress on the child and avoid shutdowns, even at the expense of completing schoolwork. This will put the child at ease and make her receptive to learning. In our view, this is the only way to instill in the child an acceptance of school work and hopefully, a desire to learn. This can be difficult for parents to advocate because they feel that by letting their child “fall behind” in school, they are doing him a disservice. This is questionable because a child having shutdowns at school is probably not benefiting at all. Instead he may be more deeply damaged every day. When the child begins to recover, parents will be encouraged by the improvement and will feel confident that they did the right thing.

Educate the teacher about your child

A teacher experienced with autistic children will probably know how to utilize low-stress teaching methods. Nonetheless, you as the parent must make sure that the learning curve for the teacher is very short when it comes to how to deal with your child.

This can be accomplished by making a detailed list of your child’s strengths, weaknesses and fears, what motivates him and what is stressful for him. Describe a shutdown and what is likely to trigger it. Make sure the teacher knows how to handle signs of stress in your child. This list should be discussed with the teacher, and given to her, before school begins so the teacher is forewarned and will be able to avoid shutdowns even on the first day of school. Get the teacher’s phone number and make a point of checking with her regularly to assure that your child is avoiding shutdowns in class.

Low-stress teaching methods that were effective with the SD child

Flexibility:

The SD child responded well to a patient teacher and a flexible learning environment which allowed the child to direct certain activities. This gave the child a much needed sense of power and control.

Controlling social pressure:

The SD child was sensitive to social pressure to perform tasks that were difficult for her. We were able to reduce the social pressure on her by giving her more time, creating social distance, allowing refresh breaks and rest breaks.

- Focus on the positive

Use “Errorless” teaching methods that reward attempts at responding and minimize the importance of mistakes [17]. This reduces the pressure on the child to perform correctly

- Give the child more time to respond:

The teacher should speak slowly, use simple language and wait for as long as it appears that the child is focused on the task before speaking again. Avoid repeating the instructions and in particular, rewording them, unless the child indicates he does not understand.

- Create social distance by letting the child work alone:

A socially avoidant child will be stressed by a hovering teacher, even a friendly one. Donna Williams explains, "Teachers...focus strongly on the person speaking, even prompting them to clarify whom they are addressing or whom the communication is about. Even if they get the person to respond to the prompting, they may not realize their actions burned a bridge here and the person with exposure anxiety (autism ,sic.) may become progressively more inhibited in initiating interpersonal communication on future occasions"[21].

When possible, give the child opportunities to complete tasks independently. The teacher can cover her eyes, walk away for a short time, or move to a different area of the room until the child says she is finished. Visual schedules allow the child to move from one activity to another unassisted. This gives the child a sense of competence.

- Speak through objects:

The child may want to use stuffed animals, puppets or plastic figures to complete the task "for her". The teacher can talk through these items also.

- Computers:

This is a stimulating teaching modality free from social pressure which has been shown to be effective with autistic children [18,19,20]. The visual and tactile elements which keep children interested and focused on the task, rather than being distracted or stressed by the presence of a teacher. In a 2002 study, autistic children spent more time with reading material presented on a computer and were less resistant to its use [24].

- Social Stories:

Social stories are also an effective, indirect teaching method [23]. They allow for communication to the child without pressuring him to respond

Refresh breaks:

Distract the child physically for a few seconds and have her take a deep breath. Variations include various stretches, wiggling legs and arms, tickling, making funnyfaces. These breaks relieve tension and are fun for the child.

Rest Breaks:

Rest breaks should be given if the other methods fail and they should be as neutral as possible. The child should not be given toys or other distractions, but should be encouraged to put his head down on the desk or something along those lines. Rest breaks of 3-10 minutes were effective for the SD child. After 3 minutes the child was asked whether she was ready to work again. If the child said "no" she was given another 3 minutes. If a shutdown occurs, the child should be provided a special safe place to rest such as a portable tent or a quiet corner of the classroom.

Simplify difficult tasks:

Tasks should be reduced into small parts. Only one part at a time, should be shown to the child so he does not become overwhelmed with a large number of tasks. Visual elements and manipulatives can also be added.

Does this approach work?

When the teaching project began with the SD child, she could work no longer than 10 min on a subject before exhibiting a stress reaction. She required 3 or 4 breaks during one hour of "school". A low-stress teaching approach was adopted to accommodate shutdowns and within 2 months the child

was able to work on tasks for up to 1 hour before exhibiting an escalating stress response. Shutdowns were virtually eliminated. The child also exhibited dramatic improvements in social and adaptive functioning as has been previously described in part 1.

Concluding remarks

The descriptions and suggestions in this paper are based upon our observation of a single child, and upon notions we have developed and connected to the literature. We wrote this paper in order to shed light on the concept of stress as a contributing factor in the symptoms and development of autism and to provide a workable intervention. We invite your comments at lmloos@hotmail.com

APPENDIX I

Description of home school academic setting:

We observed the SD child during Kindergarten-level academic lessons taught by the child's mother over a period of 10 weeks, 5 days each week. The sessions lasted approximately 1 hour with 2 breaks. Each session consisted of 3 subjects. The child and teacher were alone in a small room together, seated side by side at a desk. Each lesson was presented for 2-5 minutes followed by a task to reinforce the lesson such as copying letters or identifying a rhyming word. The goal was to work for 15 minutes on a subject before having a 5-10 minute break consisting of a fun motor activity chosen ahead of time by the child. Under no circumstances was the child allowed to avoid a task. She was required to finish it, even if long rest breaks were taken. A visual schedule was in view of the child with symbols depicting the order in which the subjects and breaks would occur. The teacher offered help as needed. Since the goal was to reduce the number of shutdowns and to increase the length of time she could stay on task without a stress response, reinforcement approaches were varied as needed.

APPENDIX II

Shutdowns in autistic adults

In April 2004, we posted a message on an internet message board (Goggle group: "alt.support.autism") for autistic adults. The posting generally described shutdowns in the SD child.

A dozen or so responders generated over 50 messages discussing the syndrome. They recognized it and indicated that shutdowns are well known among autistics, but not taken seriously by either the medical community or by their coworkers. One said, "trying to fight off shutdowns among the most stressful things I have had to deal with." Summarized descriptions include:

1. A flood of conflicting signals which makes deciding on one priority impossible.
2. Feeling suddenly very sleepy.
3. The ability to hear, move, make decisions, respond, evaluate information is shut-off.
4. Feeling confused, noisy.
5. Unawareness of the passing of time.
6. A sense of paralysis or heaviness.
7. Like a panic attack.
8. Getting tingly all over and nauseas.
9. Breathing heavily.

10. My tongue turns into a big dry sponge.
11. My sense of smell sharpens.
12. My Ears ring, eyes blur in and out.
13. I can't move because I might attract attention, which is the last thing I want.
14. Everything gets too bright and loud, running at a speed faster than normal.
15. Like having 4 drill sergeants screaming conflicting orders at you at once and if you don't do everything right away you will be in big trouble and you don't know what to do first so you stand there being yelled at.

When asked what makes a shutdown worse?

"When people tell me to "buck up", "get over it" or say, "there is nothing wrong with you".

"When people do not understand and continue to try to engage me, I may snap, get angry or start crying for no reason. I will usually be able to get over it in an hour or so if people just leave me alone."

What makes it better?

Respondents indicated time, sleep, rhythmic rocking, spinning, "stimming", working puzzles, and spending quiet time alone.

"The recovery time depends on the severity of the shutdown and whether the cause is continuing. It can last a few minutes to half an hour, with several hours of after effects."

Autistic writer Donna Williams recalls that as a child she was afraid of "the big black nothingness coming to eat me". As an adult she recognized the syndrome as "sensory flooding triggering such a degree of information overload as to cause an epilepsy-like total shut down on the processing of incoming information" [21].

APPENDIX III Identifying shutdowns and triggers in your child

Here are 2 methods to help identify triggers, stress reactions and shutdowns in your child.

Method 1: Teaching exercise

In this exercise you will teach your child something on 3 different days, each in a different way. This method requires considerable planning and effort on the part of the parent so we do not suggest it unless there is a suspicion that shutdowns are occurring. Books on the subject of learning styles may be helpful but they will not replace the valuable information that this exercise gives you. It is worth the effort and you will come away with a new appreciation of teachers. The complexity of the "lesson" should depend on your child. Assembling a simple birdhouse lends itself to variation in teaching style and difficulty, depending on your child.

The lessons should be in a place that is quiet and free from obvious distractions. Sit next to him rather than facing him. It is crucial that you prepare for each lesson by having the needed materials at hand, as well as a list of questions to ask your child. It is very difficult to invent questions when you are dealing with an unhappy child and trying to take notes at the same time. On some days your child will be able to go longer than you planned. On others, the lesson may stop before you have gotten very far into it. It is important to see these contrasts in your child. Here is a sample worksheet that will keep you organized:

Day/Date: Start time:

Finish time:

Lesson type:

verbal, paper, assembly What we will do:

Questions I will ask :

Response:

Things you should look for:

How quickly does he seem to lose interest. How can you tell? What does he say to indicate he does not want to continue? What is his body language? What happens when you press him for the right answer? What happens when you offer him a small reward for continuing after he has decided he does not like the task? What kind of reward works? What doesn't? How does your response effect him?

1. Auditory day: Probably the most difficult thing for an autistic child is the try to solve a problem based on verbal information alone, and to provide a verbal response. Do not use drawings or objects. Just talk about the parts of a birdhouse and where they are in relation to each other. Where does the roof go? How will the bird get inside? What colors would he like to use? What kind of birds will live there? What words rhyme with "bird" and "roof" and "feather". What letter does "bird" start with?
2. Auditory and visual day: On another day, use paper and pencil for the task. You can show him a picture of a birdhouse that is assembled or have him draw one. Ask him the same sort of questions from the day before, but not exactly the same.
3. Auditory, visual and motor day: On the third day, build or decorate an actual birdhouse. The lesson should be as hands on as possible. Be sure to ask him the same sort of questions, yet different from previous days.

Method 2: Observation and checklists

These lists may help parents find patterns of stress reactions and shutdowns in their children. The first step is to recognize behavior which may be brought on by stress. It does not have to be exactly like the shutdowns described herein. Perhaps your child does something that is not on this list. If you believe your child may be suffering shutdowns, take the second step of working backwards from the shutdowns to discover the sequence of events leading to them. The child should be observed during a few weeks under varying circumstances in order to uncover these patterns. It is also important to notice when the child seems particularly happy and relaxed

List 1: Possible stress reactions- What does your child do when he is pressured to do something he resists?

- o Averting gaze-looking away from the speaker
- Distancing-choosing to sit away from others
- Turning back to others
- Interrupting speaker
- Restlessness-Inability to sit still, fidgeting
- Covering ears or eyes
- Restlessness-Inability to sit still.
- Repetitive behavior-rocking, spinning, twirling, hand-flapping
- Staring at object
- Becoming distracted by something external
- Becoming distracted by something unknown
- Making sounds

- Destruction of property
- Violence towards others-hitting, pushing, biting
- Limpness
- Sleepiness
- Verbal unresponsiveness
- Dropping objects
- Asking for help
- Requesting other activity
- Verbal refusal
- Asking to rest
- Engages in discussion unrelated to the task at hand
- Walking away
- Closing eyes
- Rubbing eyes
- Yawning
- Slumping in chair
- Can't be made to comply in order to get a reward
- Becoming more animated
- Becoming more withdrawn
- Chewing on object
- Self-Injurious behavior
- Hiding face

List 2: Triggers

What situations make your child uncooperative, angry, or withdrawn? If you see behavior which may be a shutdown, go through this list to define the triggering circumstances:

- Is there a performance expectation?
 - Performance for peer, turn taking, maintaining communication with peer.
 - Performance for parent, complying with requests, responding to questions
 - Optional participation in conversation
 - Performance for therapist/teacher responding to questions or completing tasks
 - Solitary play-no performance expectation
- Has there been a recent upsetting/difficult event?
 - When
 - What
- Physical condition of the child that day [3]
 - Physical illness
 - Medication child is taking
 - Exercise prior to activity
 - Hunger
 - Sleep problems/sleep deprivation
- Environment
 - Familiar or unfamiliar location
 - Outdoors-playground, park, trail, pool
 - Indoors- Home, school/therapy
 - Sound-noisy, quiet
 - Light- bright, dark, intermittent
 - Temperature- warm, cold
 - Weather-rain, sun, storm, wind

- Social Demographic
 - Crowding-population density in immediate area [3]
 - Age of participants
 - Presence or absence of specific people [3]
 - Level of interaction: background vs. direct communication
 - Type of adult attention [3]
 - Task demands (“Draw a circle”)
 - Descriptive comments (“It’s not in here”)
 - One step directives (“give me the pencil”)
 - Praise statements (“good job!”)
 - Correction (“that isn’t right”)
 - Inquiry (“do you need help?”)

- Activity type and sequence [3]
 - Quite indoor play- imaginary play, play-doh, puzzles
 - Academics-work with letters, numbers, sorting, matching, counting
 - Gross motor-running, jumping, riding bikes, swimming
 - Passive play- watching TV or videos
 - Computer games-educational vs. action
 - Fine motor-drawing, stringing beads, building structures
 - Play directed by an adult Play directed by peers or sibling(s)
 - Play directed by the autistic child
 - Sitting in a chair
 - Sitting on the floor
 - Listening activity such as a lesson at school

*Available at www.shutdownsandstressinautism.com/StressinAutism.pdf.

A scientific version of this paper entitled, “Shutdown States and Stress Instability in Autism” is available at www.de-poort.be/cgi-bin/Document.pl?id=374.

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