

Spirituality on the Spectrum: having autism in the Orthodox Church

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This book is not the end result of a complete thought-process, but merely the first tentative steps of a journey. I do not wish to give the impression that this is in any way complete nor that it is even completely correct. It is difficult to write for and (forgive the presumption) on behalf of such a diverse group of people as those who are on the autism spectrum.

A letter to the Church

Dear Church,

Hi. I am Monica, and I am an autist.

I'm a grown-up, too, according to the calendar anyway, and have been Orthodox for about six or seven years at the time I'm writing this.

Diagnosis came late, in my case, when I had already been Orthodox for four years, so for most of the time I've been with you we've not known. However, even before I knew I have autism myself, I noticed there is a serious lack of knowledge in the Church when it comes to adults with autism.

Mind you, that's hardly surprising. The world in general has only just caught on that autistic children grow into autistic adults, and it's not a childhood condition only. Still, we have always been there, you know, even though neither you nor we knew what was the matter. You just never saw us, because we couldn't cope. Or you saw us and thought us weird.

I write about autism, but this goes for many more people than just us autists. The Church is

in many ways inclusive. No one can be turned away – that would be a serious ignoring of commandments. When people leave or there is a conflict, this is considered a flaw.

Might I draw your attention to another flaw? You see – Church is inclusive in that there are no statements made regarding salvation of people with brain differences, people with mental problems, people whose IQ scores do not reach triple digits etc. Quite the opposite, it is frequently stated that the Church believes that Gods mercy most certainly extends to people such as us, and He'll know what to do with us.

I fully agree, He certainly will. Yet by stating that **God** will know what to do with us, you make it abundantly clear that **you** do not. By stating that because of a disorder, there's no responsibility for our salvation on our part, and God will know what to do, you basically absolve yourself – along with us – of responsibility as well.

God will know, we can be sure of that and freely depend on His mercy. Yet what are you doing in the meantime? Church is for those who are already healthy in many ways, or those who can be made healthy, but I will never not be autistic.

Many of us have at least difficulties in services, and some do not manage at all. If anything is done to help, it is usually a tolerance towards the things that we, ourselves, have come up with to survive. You don't realize how much we need predictability and reliability, and how disabling sounds and smells and touch and all the things we see can be, once we get overwhelmed by them. You may misinterpret our substandard social skills and trouble with emotions as 'not caring', but I assure you, we do care. We express it differently, or not at all, but given the chance we will show you, once you know what to look for, that we do care.

Still, all that is only a minor issue, all things considered, compared to the bigger problem of our relationship with God. Yes, God will be merciful. But in using such a statement as an excuse, you rob us of the means to develop what relationship with God we can, the best way we can. I know you probably mean it as consolation – that our salvation is not hampered by our disorder. That is good. Using that consolation, however, as an excuse not to help us find ways in which we can connect to God and grow spiritually, as a way to keep things exactly as they are because to help us do that, you might need to change more than just sticking us in a quiet corner of the church building with some earmuffs on, that is saying that you don't

want to invest the effort. Don't you know that you are throwing us entirely to Gods mercy, not because you have such unwavering belief in Gods mercy, but because you don't know what to do with us?

You know what? It's okay. It's okay not to know what to do with us. We don't know what to do with neurotypicals most of the time, so it's only fair for you to be confused about us in return. But please, help us. Our way into the heart, our way towards God goes via a slightly different route – but we still want to take it.

And autistic or no, disorder or no, disability or no, everyone's life improves by growing closer to God. Not in some distant future when all of this won't matter anymore anyway, but HERE. And NOW.

Include us. We want to grow closer to God, we want to get into the heart (as soon as we figure out what on earth that means), we just don't always do well with the available tools, and need a hand finding those that do work. We want to be a part of the Church, and part of our churches. We need your help.

We will thank you (well, probably you will have to remind us to thank you, but we will anyway) for your patience and assistance in this matter.

Kind regards,

Monica

First things first:

Disclaimers:

- *He/She/It etc...mostly I've written 'we' but where 'he' occurs, you may read whatever other gender (or lack thereof) you feel is appropriate.*
- *I am not inclined to be politically correct. I just do not see why one has to state 'I have autism' (or worse, 'I am on the autistic spectrum' as if it's some sort of playground apparatus) instead of 'I am autistic' to imply that this is not the whole of what we are, but one can say 'I am a man (or woman, see above)' and everyone will already know that it is not the whole of what we are. No insults are intended, only impatience.*
- *When it comes to severe autism, combined with intellectual disabilities, I do not have the skills to address the problems these people encounter in church and in their spiritual life. I strongly advocate that an interest should be taken in supporting spiritual growth and finding solutions for church attendance for the ENTIRE spectrum. However, while we (on the milder part of the spectrum) are sometimes better able to explain and share experiences, that does not mean we are in any way capable of doing so for those who cannot. We know our limitations and I for one hope that, by making a first tentative effort, others will pick up those parts that I by necessity have to leave for now.*

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Preface

The Autistic Adult and the Orthodox Church – the need for advocacy.

Slowly, very slowly, awareness of the existence of autism is growing in the Church, but mainly focused on children. However, autistic children grow into autistic adults. The challenge is not just how to survive services without overly upsetting the neurotypicals; the challenge is the same for us as it is for all Orthodox Christians. How to move towards theosis, unity with God? To do that, despite being Orthodox, we must at times employ unorthodox methods.

How it started

After several unsuccessful afternoons of Googling, I drew the following conclusions:

1. There is information on autism within the Orthodox Church.
2. There is quite a bit written about how to keep autistic children sedate during services.
3. There is not so much written about how to actively engage autistic children during services
4. There is nothing at all written about the difficulties adults with autism face during service.
5. There is nothing at all written about connecting to God and moving towards deification when one has an autism spectrum disorder, child or adult.

And unfortunately I was looking for information on 4 and 5.

So it seems that there is only one way to get the information I am looking for – digging it up and writing it down myself. Of course, the downside of this is that it is subject to many errors, so I engaged some friends to read along.

My experience is limited, as I'm on the spectrum, but do not represent the entire spectrum. But hopefully enough of us will find this somewhat helpful. I am Orthodox, even if I'm a convert who is still very much learning what Orthodoxy is all about. So, despite the positive experiences I have had as a Baptist, I am now Orthodox and writing from that point of view.

I have autism, and write from that point of view. Neurotypicals are of course welcome to read along, and at the end of each chapter I've added some information and advice for neurotypical priests and fellow parishioners, but I'm writing for us, we who lurk somewhere on the autism spectrum and try to survive in Church.

I am also an adult, and this appears to be something that has been overlooked – that autistic children grow into autistic adults. We don't grow out of it, although of course our behaviour and ways of handling difficult situations changes as we grow up. At the same time, expectations for adults with autism are much higher.

Why?

Why is this necessary at all? Will God not protect us and help us out in church? The short answer is – no, He doesn't.

The longer answer is, of course, yes and no. Yes, He will help us. But no, He generally doesn't suddenly take our autism from us. It is true that some of us may not experience that many problems in church, and feel that God's presence protects them from any sensory overload and other problems. That is a blessing, for sure. However, I've had one or two people tell me this; I've had over two DOZEN people share with me the problems that they face in church. That doesn't mean they do not think God helps them or that they do not experience the presence of God, just that the symptoms of autism also appear in church settings. And that is reason enough to see if something can be done.

The goal of this book

I've not written this book solely to complain about how difficult things are to us, and how much we need help. Quite the contrary: We (myself and some cyberfriends who are also orthodox, adults, and autistic) started to explore what we **are** able to do. If we can't get to where we want to be by one way, then let's go find another.

We do need help with those things that are a challenge to us, and that is why this book also includes explanations for neurotypical fellow believers.

Yet what I am attempting to do with this is to explore. Find way in which we can participate, and find what we contribute. Not just in offering opportunities for others to practice patience and tolerance, but what we actually have to offer, because of, and not

despite of, our brain difference. The roads we will have to travel to find our way towards God, may be very helpful for others as well. We're not made to be pioneers, but by necessity we have to be, and we're more than willing to share the fruits of our labour.

The words we use

It is important to mention a few words, and the way in which I use them in this book. I have found there is a lot of confusion on some issues, and it's best to clarify those before anyone gets upset.

Overstimulation/sensory overload: Too many stimuli coming in! Sensory overload occurs. Either suddenly, or gradually. The senses are sending in an overload of information that is not filtered first, and the brain has trouble keeping up. We'll often get cranky and attempt to find a quiet spot. Mind, this is not unique to autism. High-sensitive people and introverts can experience the same thing. In fact, almost anyone can experience this – it's just that our threshold is far lower than average and our recovery time far longer.

For example: you're in a very crowded place, like a mall or an indoor playground. There is noise all around you, people bumping into you, colour, light, smells...it is simply overwhelming. You'll want to go outside to get a few moments' peace and quiet from all the impressions.

Autistic shutdown: The overstimulation has gone critical, and the brain has decided it has had enough. It shuts down. Symptoms of this often include being unable to process ANY information, and an inability, or reduced ability, to go through the process of thoughts, sentence-construction, and speaking those sentences. Some report inability to feel extremities and dissociative-like symptoms. This happens on the inside – an implosion of sorts.

Autistic meltdown: When thinking about autistic children, this is often what people think of – a child throwing a massive tantrum over (seemingly) nothing. This often happens when a situation becomes unclear or unpredictable. An already incomprehensible world becomes