



Newsletter

April 2021

Pastoral Care for Autistic Adults



On February 25th the Centre organised a webinar with Erin Burnett, with the title *'Different, Not Less': Pastoral Care of Autistic Adults within Christian Churches*. Erin gives a brief summary here. The recording of her talk is on the Centre's [resources page](#).

When I was a Theology undergraduate student, I decided to write about the experiences of autistic adults in the church for my final year dissertation. The aim of the study was to contribute to a better understanding of how, with the correct support and pastoral care, autistic Christians can contribute fully as church members and even serve in positions of leadership. Churches have a duty to follow the example of Christ, who took on human form and came alongside those who were ostracised from normative society, inviting them

into the Kingdom of God.

As this was an undergraduate project, there were strict limits on the amount of people I could interview. I interviewed five participants: two autistic adults, two parents of autistic adults with high support needs, and an autism charity representative. All were regular churchgoers. Their primary recommendation for pastoral carers is to *listen*. Autism is a heterogenous condition, meaning every autistic adult presents differently, and therefore support needs to be personalised to the individual.

Autistic adults continue to be affected by misconceptions regarding autism in church environments. The issue of viewing autism as a problem to be solved, or an illness to be healed, was mentioned frequently in the literature and by interviewees. Perhaps it is neurotypicals that are in need of healing: healing from prejudice, ignorance and exclusivity.

As an autistic Christian, I have a deep desire to be part of something beyond myself, to follow the teachings of Jesus and establish the Kingdom of God on earth. I may not be the best at expressing this verbally, but this I know: God is love, and autistic people are just as capable at giving and receiving love as anyone else. Many autistic adults face a life of isolation and misunderstanding; churches can offer a community of inclusive love for such individuals.

I finish with a quote from one of my interviewees: "Being in church makes me feel part of a loving community, so very different from the mess and hate of the world".

Suggestions of what churches can do to make corporate worship more inclusive:

- Involve autistic people in every aspect of church life according to their calling, including leadership
- Listen to the prophetic voices of autistic Christians, even though their theology may differ from the norm
- Provide headphones or earplugs
- Reduce or eliminate fluorescent lighting
- Have an order of service, or a predictable pattern followed during services
- Provide a quiet room
- Share resources provided by groups such as the Autism Faith Network and the Centre for the Study of Autism and Christian Community

Louis' Lockdown Life

Kate Sainsbury is mother of Louis, an autistic young man. She reflects on the difficult time of lockdown during which she was not able to see Louis. She wrote this reflection on Good Friday, and intersperses her reflections with quotes from Psalm 22, a Psalm traditionally read on this day in their Anglican tradition.

Lockdown March 2019: widespread uncertainty, television shows lorries carrying coffins in Italy. I visit Louis in hospital. He hums *Daisy, Daisy*, says 'She's all right'. I realise he has seen Paris on the news, where his sister, Daisy, lives. Two years ago his pony died, he knows about dying.

We are all afraid. I read an Easy-guide to Coronavirus with him. Louis can't understand: none of us can. I take an iPad with wifi, just in case. Next day, the ward shuts.



My God, my God, why have you forsaken me?

Louis doesn't see me for four months. I discuss treatment plans with the doctor, I weep.

Louis learns to use FaceTime.

O my God, I cry in the daytime, but you do not answer, by night as well, but I find no rest.

In a world of not-knowing, Louis' lack of understanding is part of our landscape. Staff are kindly to the seven patients.

Routines help: mealtimes, bedtime,

FaceTime with mum.

Online we sing nursery rhymes, talk about friends.

'Bye-bye hospital!' he says.

'One day 'bye bye hospital',' I say.

Louis forcefully shouts: 'Bye bye 'one day'. Home!'

'Soon,' I promise.

I hold out HOPE. 'One day we'll have a **party!**

'Balloons! Cake!' he says

This helps.

In a world of not-knowing, worrying about Louis is 'new normal'. Staff reassure me he is fine, they take him walks, draw with him.

I hope and trust.

Our forefathers put their trust in you; they trusted and you delivered them.

After lockdown when I visit Louis' jumps with joy. 'Home!' he says.

This is not allowed.

'Soon!' I promise.

'Bye-bye 'soon'.'

Patients are admitted. The ward gets noisier. Drug usage rises.

Louis protests. Staff speak of 'challenging behaviour'.

He repeats their words. 'You are a very naughty boy! How dare you!'

I lie awake at night praying.

We walk in the countryside. Louis is happy. We picnic, pray the Lord's prayer. He says 'Hold Daddy's hand!' I recognise this is his version.

The hospital forbids our outings. Say they harm him.

But as for me, I am a worm and no man

The darkness covers us.

He is prone restrained, injected with drugs. He shrieks the emergency alarm sound.

I tell him I love him.

He cries and I comfort him.

Be not far away, O Lord, you are my strength, hasten to help me.

Postscript

After these sorrows, Louis moved last month to a smaller unit specialising in learning disabilities. He is happier, well-cared for. We are planning his move to his own home, empowering him and the care team through therapeutic trauma-healing approaches. On Easter Day we celebrated the joy of new life when he came home for the day.

Upcoming Webinar: Autism and Sensory Processing

When? The Centre organises its next webinar on May 20th, 11:00-12:30 (British Summer Time, BST), with Dr Katy Unwin. Registration details will be sent later.

What? Dr Unwin will provide an overview into sensory processing in autism from a psychological and neuroscientific perspective. She will discuss (1) current research in the field of sensory processing in autism, (2) her findings on the use of Multi-Sensory Environments with autistic children, and (3) her current work aiming to decrease the age of autism diagnosis through sensory symptoms.

Who? Dr Katy Unwin is postdoctoral Research Fellow at the Olga Tennison Autism Research Centre, La Trobe University in Melbourne, Australia. You can find out more about her on her website: <https://www.drkatyunwin.com/>.



Dr Katy Unwin and our Centre's co-director Dr Léon van Ommen were jointly awarded a Summer Fellowship from the New Visions in Theological Anthropology (NViTA) project, based at the University of St. Andrew's. They will collaborate on a project titled *The Effects of Sensory Issues on the Experience of Worship by Autistic People*. More about this project in the next newsletter and soon on our website!

Research Project: The Lived Experience of the Church of England Eucharist by Autistic People

Denise Maud is PhD student at the University of Aberdeen. Here she tells us about her research project. If you want to find out more about the research that takes place within the Centre, click [here](#).

My research project is considering the lived experience of the Church of England Eucharist by autistic people. I'm a Church of England priest and a Mum to an autistic 12 year old. The inspiration for my research has come from my son who, although officially diagnosed autistic 4 years ago, I've known since he was about 4 or 5 that he was autistic and that

he experiences the world differently to how I, a non-autistic person, experience the world. It has been a learning journey for both of us as I learn from him how he lives his life as an autistic person and how best I can walk alongside him on that journey. As his Mum I have seen first-hand the prejudices and assumptions that others make about him. Some of the many comments we hear regularly are 'he is naughty'; 'I'm a bad parent'; 'he doesn't concentrate'; 'he needs to learn to not interrupt, needs to sit still ...'; 'it's because he's a boy, all boys are like that'; 'we're all a bit autistic aren't we?'

Church, a place where in theory all should be welcome, was difficult for him however he was able to engage in the Eucharistic part of the service and it led me to wonder why this might be so. As I began my research project it came to light that the voices of autistic people are very rarely heard in respect of church worship and community. Participation in the Eucharist is a part of Christian worship where all are welcome to the Lord's table. However, the question whether autistic people are made to feel welcome at that table or if, by whatever means, they feel, or are, excluded, is under-researched.

As a non-autistic I am mindful of the hurt (and in some situations harm) that the autistic community have felt through research being carried out by non-autistic people and the assumptions that have been placed on the autistic community. At the heart of my research is the autistic lived experience and their voice. It is hoped through their voice we will come to learn about the lived experience of the Eucharist and what may need changing in order to ensure all are welcome at the Lord's table.



Centre for the Study of Autism and Christian Community



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