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Faith In a Pandemic

– hearing from families with children who have additional needs

by Mark Arnold, Additional Needs Ministry Director, Urban Saints

It's been a bit of a year so far hasn't it? Back in January when we heralded in the New Year we thought Brexit and the US Presidential elections would be the big stories of the year; they still are, but they've been trumped (do you see what I did there!) by the other, non-Republican, elephant in the room, COVID-19.

The coronavirus pandemic has brought about changes that none of us could have anticipated, a need to adapt that none of us were prepared for and a future that remains uncertain for us all. These unprecedented times have been challenging for everyone, but for children and young people who journey with additional needs or disabilities, and their families, the struggle has been even greater. Parents/carers that have been used to social isolation and exclusion, for whom the difficult juggling of home life, work life, school, medical appointments and lots of other 'balls' is familiar, have experienced all of this being raised to a whole new level. Families that have been used to operating 'on the edge' have found that COVID-19 has handed them that 'final straw' that has tipped them over it. It's been so hard for so many.

A recent survey of parents/carers by the Disabled Children's Partnership found that the situation in families through lockdown has been, and continues to be, quite stark.

Parents reported that the level of care they were needing to provide has increased significantly, with 72% of parents/carers saying they were providing 'a lot more care compared with the amount before lockdown'. Siblings were being drafted in to help too, with 68% of parents/carers saying that non-disabled siblings were 'providing a lot more care'.

All this in response to a collapse in the support offered to families, with half of parents/carers saying that the extra support or therapies for their children, that they had in place before lockdown, had stopped. For families that had

received access to short respite breaks before lockdown, three-quarters reported that this respite care had stopped. Lockdown has been affecting assessments too, with two-thirds of families experiencing delays with assessments and approaching half of families saying that annual reviews had lapsed or been put on hold.

Consequences of these issues are serious, with half of families not seeking necessary medical health support for their disabled children, for themselves, or for their non-disabled children.

The overwhelming majority of families have seen a decline in the mental health of their children and themselves, with over half of families also saying that either their physical health, and/or their children's, had worsened.

Families are facing financial pressures too, with a reduction in income affecting over a third of families, and increased costs impacting on nearly two-thirds. One in five families said they will go into debt as a result of lockdown.

It's a stark picture, and one that many of us will recognise. The Disabled Children's Partnership is using this data to lobby for acknowledgement of the situation that many families of children with additional needs or disabilities are facing, and for increased support and flexibility to help families.

For the full report from the Disabled Children's Partnership, including many quotes from families that were asked for their views, visit:

<https://disabledchildrenspartnership.org.uk/wp-content/uploads/2020/06/LeftInLockdown-Parent-carers'-experiences-of-lockdown-June-2020.pdf>

As someone whose faith is vitally important to me now, as it has been all my life, I've found myself asking loads of hard questions as I've seen so many struggling and suffering this year, including

among the families that I know with children with additional needs. Where is God in all of this? What is the role of the church? What can I do?

One of many things that Jesus did brilliantly was to shine a light on the lives of marginalised people and to give them a voice. Take Bartimaeus, for example, a man born blind who begged on the side of the road to Jericho. He heard Jesus and his followers going by and called out to him; Jesus heard Bartimaeus and asked for him to be brought to him. Now Jesus had been going around preaching, teaching and healing people and so the crowd gathered around, waiting for another amazing miracle. But Jesus did something really important and significant first. He asked Bartimaeus a question, 'What do you want me to do for you?'

What an extraordinary question to ask! Everyone knew that Bartimaeus was blind, Jesus knew that Bartimaeus was blind, and as God made flesh he knew what Bartimaeus wanted. So why did he ask? Jesus taught us not to assume that we know what people want, not to decide for them, not to make decisions on their behalf, but to ask, to hear people, to give them the dignity and respect of articulating for themselves whether and how they want to be helped.

I love this story, it's a favourite of mine, and so it got me thinking about the families that we journey with through the Additional Needs Alliance, a collective of parents and carers, children's, youth and families workers, practitioners, anyone who cares about children, young people and young adults with additional needs or disabilities. In the midst of the pandemic, and as part of the preparation for a conference, we took a lead from Jesus' example and asked them some really important questions. As you might expect, the responses were mixed:

What has lockdown been like for you? What has been bad/negative, what has been good/positive?

'It's been a horrendous, lonely and a generally trying time. No respite and numerous meltdowns from my son and it has been difficult to keep my family safe at times. Little sleep. Exhausting. It's really made our family reach breaking point.'

'Full lockdown was great. No sensory meltdowns, no forcing clothes on and having to get to places on time. We home educate so didn't have the pressure of school, we just started our summer holidays early and found a new rhythm.'

What has your church done to support your family and help you to nurture the faith development of your child?

'Sadly, absolutely nothing. Not heard personally from anybody from our church. This has made us feel really sad and our faith is hanging by a very thin thread.'

'Our church has been truly amazing. They have provided meals for us every day for four weeks while I was at my most unwell. Members of the church have got us milk every few days, done our shopping, collected my son's (many) prescriptions. As well as that they have provided twice weekly Zoom meetings for the children. They live streamed two services a week for the majority of lockdown, one aimed at the children and one more traditional service.'

What else could church do to support your family and help you to nurture the faith development of your child?

'Make contact. Check on my children, make them feel part of our church and loved. Offer us an hour of respite so I can get a little break or some time with my other children. But really just some contact, to make us feel like we are part of the church, that people are

