

## TALKING THE WALK

# Learning, leaning, leading

Episode 39 | Mark Arnold

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Mark Arnold's job title is fairly unique: he's the Additional Needs Ministry Director for the Christian charity Urban Saints.<sup>1</sup> The aim of his ministry is 'to encourage, enable and equip children's, youth and families' workers to reach, include, create belonging for, and disciple all children and young people, especially those with additional needs or disabilities.'

On his blog, *The Additional Needs Blogfather*, Mark recently wrote about the Japanese concept of *ikigai*<sup>2</sup> – the meaning of which encapsulates that sweet spot of doing what you love, what you're good at, what the world needs and what you can get paid for.

'I don't really think about what I do as "work" anymore. It's what I'm "meant" to do, it's what gets me out of bed in the morning. If a distant relative that I had never known happened to leave me a million pounds, I would still do what I do. I can't *not* do it – it's my calling, my *ikigai*.'

It's clear from this episode of [The All Terrain Podcast](#) that Mark's calling is the result of a 20-year journey of being dad to James: a 20-year-old autistic young man with epilepsy, learning difficulties and anxiety. In Mark's conversation with Jo, he shares lovingly about the joys of being James's dad – and about how much he has learnt, grown and changed through James's positive impact in his life.

## Learning

Exploring an unexpected new destination

Mark re-tells a story that Emily Perl Kingsley wrote to illustrate the experience of raising a child with a disability for those who have not shared that experience.<sup>3</sup> She likens it to spending months planning and eagerly anticipating a once-in-a-lifetime holiday to Rome, only to touch down at the airport and hear the flight attendant announce, 'Welcome to Holland!'

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<sup>1</sup> He's also a [Churches for All](#) partner, a member of the [Council for Disabled Children](#), co-founder of [The Additional Needs Alliance](#), founder of [The Dads' Fire Circle](#) and the author of [How to Include Autistic Children and Young People in Church](#)

<sup>2</sup> ['What is your 'ikigai', your 'calling'?'](#)

<sup>3</sup> ['Welcome to Holland'](#)

While there would be an understandable anger at being taken somewhere other than the place of your dreams, what's important in this scenario is that you've not been taken somewhere horrible, just different.

As someone who's worked with lots of parents who are trying to come to terms with the fact that their child has some form of additional needs, Mark says he's witnessed all sorts of responses.

'There will be those families who are in denial and angry, who want to be put back on a plane that's going to Rome. But there will be the families that emerge blinking into the Dutch sunlight and go and have a look at what Holland's got to offer.'

### Results day

'It's so hard to see folks that are struggling through times of challenge and who are just not able to get to that place of acceptance,' says Mark. 'But right at the beginning of our journey with James, I was probably there too – and there are still times when I can spiral back into that if I'm not careful.'

'A couple of years ago on A-level results day I happened to be watching BBC News. The programme showed lots of A-level students jumping in the air, excitedly waving their results papers.'

'And in that moment it struck me that James, who was never going to be doing A-levels, would have been in this year group and would have received his A-level results that day if he had been on a different journey. And for a moment that 'stabbed' me a bit.'

'But a few moments later I heard James in his den, belly laughing about something that that he was watching. I wandered in, and he gave me a great big beaming smile and invited me to sit with him. And I gave him a hug. And all those negative thoughts just drifted away.'

### 1000 gifts

As James grew up, epilepsy and anxiety were added to his list of additional needs, and at one point he was unable to leave the house for 14 months.

'It was incredibly hard, because we were very restricted in what we could do as a family, but also really concerned for James being stuck in the four walls of the house.'

'One of the things that was a game changer for us during that time was the book, *One Thousand Gifts*.<sup>4</sup> It encourages you to identify three things every day to be thankful for, and to write them down.'

'Some days, trying to find three things was really hard – but every day I would write down three things that I was thankful for. And over the course of a year, that gives you 1000 "gifts", which you can look back on in those really tough days. Yeah, there are challenges – but there are good things still happening even in the midst. Even when you feel you're dying there in the pit, God's there too.'

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<sup>4</sup> *One Thousand Gifts: A Dare to Live Fully Right Where You Are*, by Ann Voskamp

## Leaning

### Being in the right place

When he was growing up, Mark spent lots of time by the River Stour in Bournemouth. The river is great for swimming or fishing in, but as you move further in it suddenly drops into a deep channel.

As an adult, Mark saved a boy in the same river. He'd been walking along the bank, listening to the sounds of the birds and insects, and had heard a mum calling out to her son, Freddie, who was fishing (and ignoring her). Seeing Freddie move deeper into the water, he rapidly set down his phone and wallet and ran into the water as he saw Freddie disappear into the deep channel. Reaching the channel and looking down, he saw a flash of his brightly-coloured t-shirt and managed to grab him and haul him back up. Moments later and he would have drowned.

Reflecting about the moment Mark says, 'I think sometimes, especially when we go on a bit of a walk with God, stuff can happen. God can put us in situations. We can find ourselves encountering people or situations that makes you think afterwards, "God put me there in that moment, for that reason." And so, listening and watching and seeing all that's around us can be really key to making sure we don't miss those moments.'

- ☰ *Being saved from drowning had a life-changing impact on Freddie – but in what ways do you think it might have impacted Mark?*
- ☰ *Have you ever had a moment you felt that you were in the right place at the right time? What happened? Did you get a sense that God had put you there in that moment?*
- ☰ *How do you listen and watch for what's going on around you to make sure you don't miss those 'God' moments? If you're unsure how to answer this question, is there anyone you see as spiritually wise that you could ask to teach you?*

## Leading

### Creating a space in which everyone can belong

Mark tells us about a recent resource he was involved in.

['Invited to Belong'](#) is a joint collaboration created by Youthscape and Urban Saints. We created this six-part programme that helps children's and youth workers to understand additional needs of various kinds, to be inspired by stories of inclusion and belonging, and to hear what Jesus has to say about all of this.'

- ☰ *Does this programme sound like something that you or people in your church would benefit from?*
- ☰ *Are you aware of people with additional needs in your church? How does the church support and care for them? How do you support and care for them? How might Jesus support and care for them?*



## Crying at the tip

Mark will forever remember the difficult period when James felt unable to leave the house. Whenever he or his wife wanted to leave the house, the other would have to stay at home to look after James. While they always gave James the opportunity to go out with them, for 14 months he had always refused.

'It was August and I had filled the car with stuff from the garden to take down to the tip. In the past, James had loved coming down to the tip with me and watching everything get chucked over the side. So I just went into his den and said, "Hey, James, I'm going to the tip, do you want to come?" He just got up and headed down the hall towards the front door.

'As we went through the front door and out to the car I suddenly realised that the seat James usually sat in was folded down and full of garden stuff. I quickly skirted him around to the front passenger seat, which he'd very rarely sat in, but he got in and suddenly we were driving off down to the tip.

'It might not sound like a big deal. But it was the first time in 14 months of James had gone anywhere. I don't know how we got there and back, because I'm not sure I could see through the tears of joy I was crying in that moment. And I was just so thankful to God. I didn't know if that was just a one-off, and we'd go through a long period again. But as it turned out, that was the breakthrough which then unlocked other things. I'll never forget the joy of that moment, and how thankful I was to God for that.

'I'm absolutely certain that I was the happiest person at the tip that day – and not just on that day, but possibly on every day that I've ever been to the tip. When James and I were there, it was just one of the best days I can ever remember. I was so thankful: It really wasn't hard to write my three "gifts" down in my journal that night. The hardest thing was to know which three to pick!'

## Is there place for not accepting?

Jo asks Mark if there is place for people fighting for, or even hoping for, something better for their children with additional needs.

'You can choose not to accept the way society treats people with additional needs and disabilities. The system can make it hard for families to access the support they need. There are much longer waiting times to get a diagnosis now than three years ago. So it's right to challenge that, and demand better.

'But I think we can be fighting for change and fighting for better for our children *whilst at the same time* wholly and completely accepting them for who they are.'

## Your prayers change

'James was two and a half when he was diagnosed as autistic and having learning difficulties.

'I remember bringing that to God, and essentially my prayer was: "Please take this away from James." God didn't take it away. Instead, he gave us a greater understanding and a willingness to use the journey that we were on, and are still on, to help others.

'I don't pray today that James would not be autistic or not have learning difficulties, because they are key parts of who James is. If James wasn't autistic, he wouldn't be James. What I pray *now* is that God helps us to use the journey we're on to help others. And that God helps us to help James and to understand James better.

'And so the change that we're asking God for now is more about change in us rather than James. And I think that's a key breakthrough that came to us as we went on that particular journey.'

☞ *Mark often uses the metaphor of being on a journey to talk about his life. Why?*

☞ *Is there anything you prayed about and found your specific requests to God changing? Why did your prayers change?*

## Learning, leaning and leading with others

'We mature in service by learning every day, leaning every day, and leading every day.

'It doesn't matter how long we've been on this journey, there's always stuff that we can **learn**. And it's so important to look for those times to learn because they give us more that we can use as we serve others – wisdom we can pass on, curate and collate and offer back to people.

'**Leaning** every day means leaning into Jesus, leaning into what he's showing us how he's guiding us. Asking him to open our eyes and our ears help us to sense what's going on around us. What's he showing us? What's he guiding us towards? What does he want us to do to join in with him?

'And those things then help us to **lead**: to use what we've got to shape things and to serve others, to bring what we've learned and received from God to be able to make a difference for other people.

'But what brings all of that together is to do learn, lean and lead **with friends** – not to do it alone, but to do it with others. It means we can keep each other accountable and check in on each other, pray for each other, hug each other when we're doing this journey with others.

'I know that I would struggle hugely to do any of the stuff that I do without good friends that are there to, to be on the journey to and that make the world of difference.'

☞ *Mark suggests that our ability to lead – that is, to make a difference in the world – is dependent on two things: learning from the journey we're on and leaning into Jesus. Do you agree? Which do you find it harder to do?*

☞ *Some leaders struggle with loneliness because they keep a distance from those they lead, but Mark suggests we should lead in the context of friendship. If you led alongside people who checked in on you, challenged you gently, prayed for you and hugged you on a regular basis, how would that impact your leadership?*

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