

Keywords: A Vocabulary of Child Disability

Dan McEvoy

Suggested interview questions for journalists, podcasters, and event organisers. The author is happy to adapt or expand on any of these topics. Questions may be used in any order or combination.

THE BOOK & ITS METHOD

What is *Keywords* about, in a sentence?

It's a book that takes 177 words and phrases from the vocabulary surrounding disabled children — clinical terms, policy language, things strangers say to you in supermarkets — and examines what each word is actually doing. Not what it means in the dictionary sense, but what ideological work it performs.

Why Raymond Williams? What does his method offer that a dictionary or glossary doesn't?

A dictionary tells you what a word means. Williams' method asks what a word *does*. When he examined a word like *welfare*, he wasn't interested in its definition. He was interested in the fact that it had accumulated contradictory meanings — generosity and surveillance, support and control — and that people used it without noticing the contradiction. The vocabulary of child disability is full of words like that. *Care* means tenderness and it means warehousing. *Special* was meant to liberate and became a mechanism for segregation. Williams gives you the tools to see how that happens.

You describe words as 'tiny engines of ideology.' Can you give an example of how that works in practice?

Take the word *need*. It appears in almost every piece of legislation governing disabled children's lives in Britain. The Children Act 1989, the Care Act 2014, the SEND Code of Practice — all of them are structured around identifying and meeting children's *needs*. It sounds child-centred. It sounds compassionate. But look at what the word actually does in those systems: it converts a child's right to support into a claim that must be assessed, evidenced, and rationed against a budget. The word looks like it's about the child. It's about the budget. That's what I mean by a tiny engine of ideology. The word does the political work so quietly that nobody notices.

177 entries is an enormous number. How did you decide which words to include?

I started with the words that had been used about my daughter, or to me, or in meetings about her. That gave me the clinical vocabulary, the policy vocabulary, and the everyday

vocabulary. Then I expanded outward — historical terms like *idiot* and *feeble-minded* that created the institutional frameworks still shaping services today, and contemporary terms like *SEND* and *person-centred* that carry progressive intentions but have been captured by bureaucratic systems. The test for inclusion was always: is this word doing more than it appears to be doing? If yes, it earned an entry.

THE PERSONAL DIMENSION

You say the book began with the word ‘sorry.’ What happened?

People said *sorry* to me constantly after Elisa was born. In hospitals, in supermarkets, at school gates. Always well-intentioned. And at some point I realised that the word wasn't simply a response to my circumstances. It was converting my daughter's existence into a tragedy in the first seconds of every conversation. She was alive. She was present. And the first word the culture reached for was the word it uses for bereavement. Nobody meant to do that. The word did it for them. That's when I understood that the vocabulary itself was a system worth examining.

Your daughter Elisa is central to this book. How do you navigate writing about her analytically while honouring her as a person?

That tension is the book. I can't pretend to be a detached observer. I spent a decade living inside the language this book examines — not studying it from outside, but having it applied to my daughter, daily. But Williams' method helps, because it's not about telling people what to feel. It's about showing how words work. When I write about *quality of life*, I'm not saying people shouldn't use the phrase. I'm showing what the phrase does — how it converts a child's lived experience into a clinical metric that can be weighed against the cost of keeping them alive. That's analytical. But it's also personal, because someone used that phrase about Elisa.

You were diagnosed as autistic at forty-eight. How does that shape the book?

It gives me a double perspective. I'm writing about the vocabulary applied to disabled children as a parent, but I also have my own relationship with vocabularies of deficit and difference. I know what it's like to have a word applied to you that changes how you're seen. Diagnosis can be liberating and it can be constraining, and the language that surrounds it determines which of those things it becomes. That's true for autism and it's true for every condition examined in this book.

The word ‘special’ is one that most people would consider positive. What does your analysis reveal?

Special was introduced by the Warnock Report in 1978 specifically to replace the medical categories that had been used to classify disabled children — terms like *educationally subnormal* and *maladjusted*. It was a progressive move. But within a generation, *special* had become a sorting mechanism. Special needs. Special schools. Special provision. The word that was meant to include became the word that separated. Every parent of a disabled child in Britain knows exactly what *special* really means in a meeting: it means your child is being moved somewhere else.

You include historical terms like ‘idiot’ and ‘monster.’ Why look at language that’s no longer in use?

Because it is still in use, structurally. The word *idiot* was a clinical classification in British law until shockingly recently. It shaped the institutions that housed disabled people, the funding structures that paid for them, and the professional hierarchies that managed them. Retiring the word didn’t retire the structures. And *monster* — from the Latin *monere*, to warn — traces a three-thousand-year-old pattern of reading disabled bodies as signs, as messages from the gods, as texts to be interpreted for meanings that serve everyone except the person themselves. That pattern persists in the charity poster, in the inspiration story, in the way people look at a disabled child in public. The word has been retired. The gaze hasn’t.

Are there entries that surprised you in what you found?

The entry on *care* was revelatory. The word carries this warmth — we speak of caring for someone, of care and compassion. But trace it historically and you find that *care* has also always meant anxiety, worry, burden. The Old English *caru* is closer to grief than to tenderness. And when you look at how the word operates in policy — care homes, care packages, care plans — it’s the institutional meaning that dominates. The history of disabled children is the history of that ambiguity being exploited: using the warm meaning to justify the cold practice.

This is a book about British language and policy. Does the analysis apply elsewhere?

The specific legislation and institutional history is British, but the linguistic mechanisms are not. The pattern of using euphemism to manage anxiety about disability, of converting children's rights into rationed resources through the language of need, of sentimentalising disabled children to avoid addressing structural inequality — these are present in every English-speaking country and most others. The word choices differ. The machinery is the same.

The book is analytical rather than prescriptive. But do you think language should change?

Williams didn't tell his readers which meaning of *culture* to adopt. He showed them that the word carried several competing meanings and that the competition was itself a political struggle. I've tried to do the same. I don't think the solution is finding better words. The history of disability language is a history of euphemism replacing euphemism, each new term becoming contaminated within a generation. *Handicapped* replaced *crippled*. *Disabled* replaced *handicapped*. *Special* replaced everything and became worse than all of them. What I want is for people to hear the machinery. If you can hear the word working, it loses some of its power over you.

Who is this book for?

It's for parents who have sat in meetings and felt that the words being used about their child were doing something they couldn't quite name. It's for professionals who use the vocabulary of their sector daily and have begun to suspect that the language is not as neutral as it pretends. It's for disabled people who have lived inside these words and want to see the machinery taken apart. And it's for anyone who believes that how a society talks about its most vulnerable children reveals what that society actually is.

If a reader only has time for three entries, which would you recommend?

Sorry, because it's where the book began and it shows the method at its most personal. *Need*, because it reveals how an apparently compassionate word operates as a rationing mechanism at the heart of British social policy. And *Monster*, because it traces a pattern that's three thousand years old and still operating in the charity poster and the inspiration story. Together they show the range of the book: the everyday, the bureaucratic, and the historical, all connected.

Why self-publish through your own press rather than go with an academic publisher?

The book sits between disciplines and between audiences. An academic publisher would market it to disability studies scholars, which is one audience but not the only one. The parents sitting in EHCP meetings, the social workers filling out assessment forms, the strangers who say *sorry* — they need access to this analysis too, and they won't find it through an academic press at academic prices. Self-publishing through Small Engine Press lets me control pricing, distribution, and format. The name is from the book's own language: words as 'tiny engines of ideology.'

What has writing this book changed for you?

I hear the words differently now. I can't unhear them. When someone uses the word *resilience* about a family with a disabled child, I hear the system congratulating people for surviving what it has failed to support. When I see the word *inclusion* in a policy document, I look for the word *reasonable* nearby, because that's the word that will undo it. Whether that's a loss or a gain, I'm not sure. But I think more people should hear what I hear. That's why the book exists.

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The author is available for interview by phone, video, or in writing. These questions may be used in full, adapted, or used as a starting point for a different conversation. Individual entries from the book are available as standalone extracts by arrangement.