

# The Book of Experiences

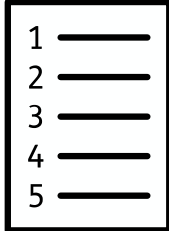
Widgit Symbols © Widgit Software 2002 - 2019 [www.widgit.com](http://www.widgit.com)



**Comisiynydd  
Plant Cymru**  
Children's  
Commissioner  
for Wales



The Book of Experiences is our 3rd report about **Regional Partnership Boards (RPBs)**. You can read the other reports here.



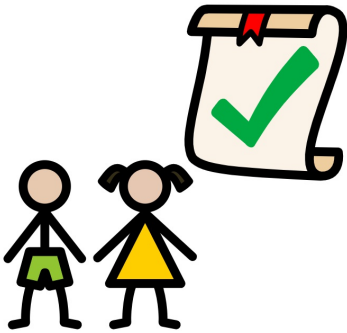
This report includes some tricky words. We've highlighted them in **blue**. Use the word list to help you.



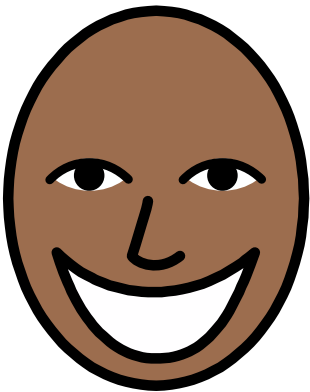
# The Children's Commissioner for Wales



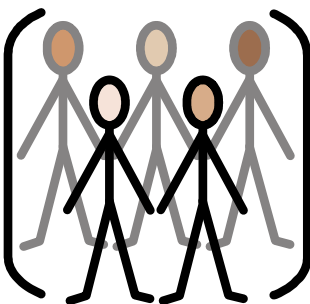
This is Rocio Cifuentes. She is the Children's Commissioner for Wales.



Her role is to make sure that all children and young people in Wales get their children's rights.



Children's rights are the things you need to grow up feeling happy, healthy and safe.



Rocio and her team have worked with young people and their families to write this book.



## Message from Rocio Cifuentes



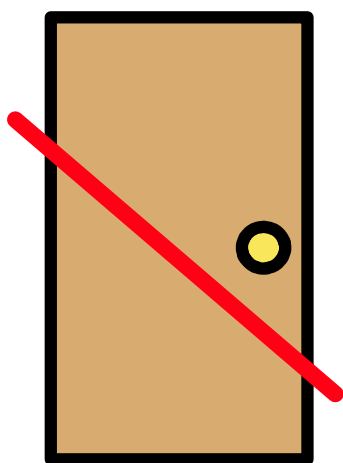
The lack of support for **neurodivergent** children and their families is something we've been worried about for a long time.



Children and young people often have to wait a really long time for an assessment.

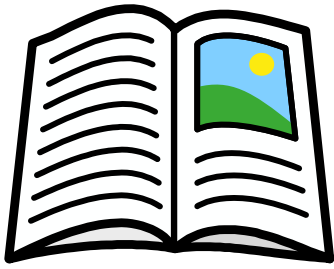


There is little or no support for children and young people who are waiting a long time for an assessment.

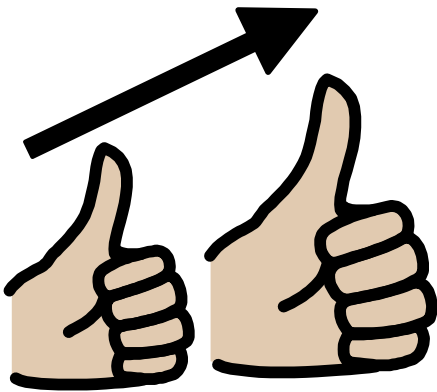


We're calling for a '**no wrong door**' response, so that services work together better to help children and young people, to make sure that children and their families haven't got to face a complicated system to get the support they need.





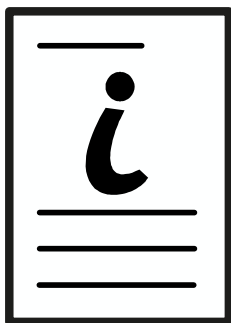
This is a book of experiences – of real life stories and barriers that children and their families have faced.



We've got to do better and we've got to improve. We hope that Welsh Government will listen to these stories and accept how difficult it is for some children and their families at the moment.



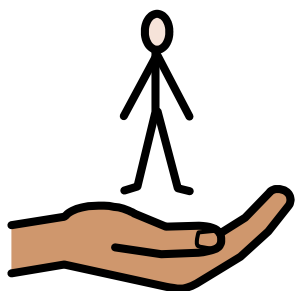
## What is a Book of Experiences?



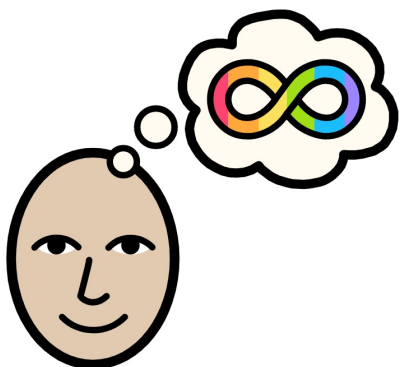
Book of Experiences is the name we gave this report. We called it that because in this report we have asked children, young people and their families about their experiences.



Experiences means the things that happen to you in your life.

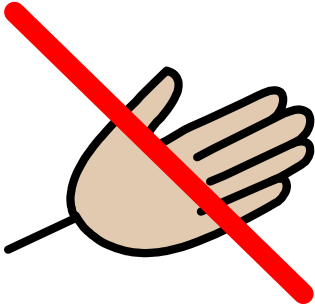


The experiences in this book are about children, young people and their families waiting for an assessment for a **Neurodevelopmental condition**.

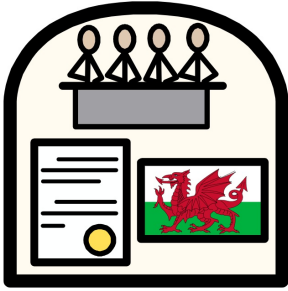


**Neurodevelopmental** conditions are a group of conditions which can be described by the way in which the brain develops. This includes lots of different conditions, but some examples are Autism Spectrum Disorder, Dyslexia, Dyspraxia, Attention Deficit Hyperactivity Disorder, or Tourette's and tics.





The experiences that the families share in this book are about not having help or support while they wait for an assessment.



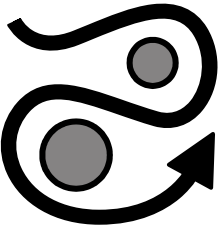
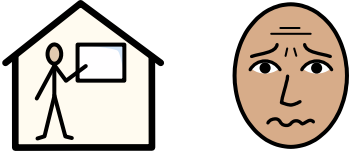



We thought it was important to put all of their experiences together to remind Welsh Government, Regional Partnership Boards (RPB) and other organisations that families still need help.



## The Experiences

In the book, we have three stories, of C, N and E. Although each story and experience is different, there are common issues:

	Children and their families left with little support
	Children having to wait a long time for assessment
	Children and their families having to navigate between lots of services trying to get support
	School life difficult
	Lives being put on hold

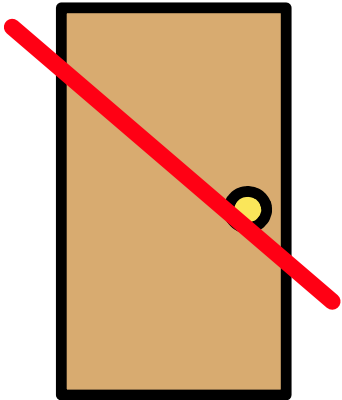






## What families would like to see

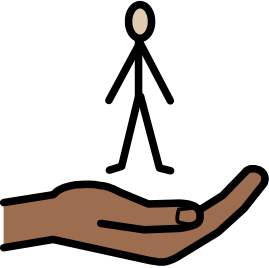
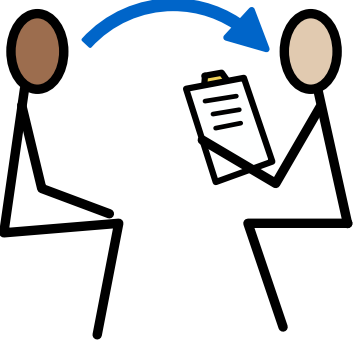

We asked families what they thought would help them and other families. They told us about things that helped them and things they would like to be different.

We have put them in a list.

	<p><b>No Wrong Door</b></p> <p>Families have told us that they would like services to be able to help their child. If they can't help families would like them to send them to the people who can. Families told us that having to wait for every service means their children are growing older without getting support.</p>
	<p><b>Respectful Communication</b></p> <p>Children and young people said they wanted to be spoken to in a respectful and age appropriate way.</p> <p>Families told us they would like the opportunity to talk to professionals away from their children.</p>
	<p><b>Welsh language</b></p> <p>Families told us that it was important to them for their children to have access to the services they needed in their first language.</p>


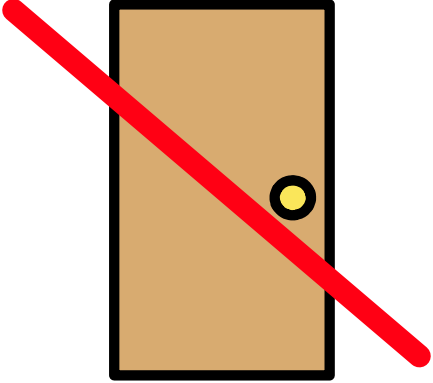



## What families would like to see

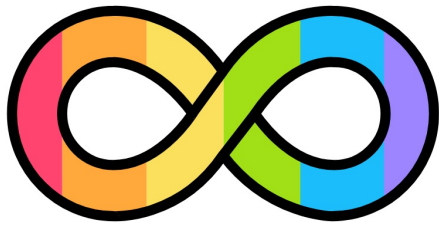
	<p><b>Transitions</b></p> <p>Families want better support for their children when they move to another school or service.</p>
	<p><b>The Process</b></p> <p>Families would like services to work together and ensure that everyone understands their role in the process and what is needed to get a child/ young person the appropriate assessment and support they need.</p>
	<p><b>Support for families</b></p> <p>Families told us that they would like Local Authorities and Health boards to review current support available locally and fund more peer-to-peer support groups where possible.</p>



## Word list

	<p><b>Regional Partnership Boards</b></p> <p>The government created 7 Regional Partnership Boards in Wales. They are in charge of making sure that services like the health service and social care work together.</p>
	<p><b>No Wrong Door</b></p> <p>The approach the Children's Commissioner has called for, for young people to get the help they need wherever they ask for it – so they aren't told they've knocked on the 'wrong door'</p>
	<p><b>NEST/ NYTH</b></p> <p>NEST stands for Nurturing; Empowering; Safe; Trusted. NEST / NYTH is the name of a plan for every region of Wales to create a wraparound support system for children and young people's mental health and wellbeing. It aims to make expertise and advice quicker to access, and to support adults supporting children to have the tools they need to help.</p>

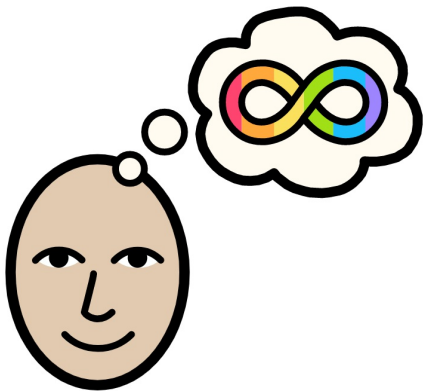




## Neurodiversity and neurodivergence

When we talk about neurodiversity, we are recognising that we all have different ways of thinking and feeling, and that our brains work differently from each other.

Neurodivergence means that the brain works in ways that are different from what are considered 'typical'. This could be because of what we might call a neurodevelopmental condition, a learning disability, or it could be because of the effects of physical differences, such as an acquired brain injury.



## Neurodevelopmental conditions

Neurodevelopmental conditions are a group of conditions which can be described by the way in which the brain develops. This includes lots of different conditions, but some examples are Autism Spectrum Disorder, Dyslexia, Dyspraxia, Attention Deficit Hyperactivity Disorder, or Tourette's and tics.

