

# How we make mainstream education work for our disabled children

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# Introduction

My 6-year-old son, Ivor, was diagnosed with Angelman syndrome, 3 years ago.

I want to talk to you about my experience of mainstream education with Ivor; what works and how children with additional needs can be fully included.



# What is Angelman syndrome?

- Angelman syndrome is a neurogenetic disorder affecting about 1 in 15,000 people, or about 500,000 individuals worldwide; about 200 people here in Wales.
- People living with Angelman syndrome have a **genetic difference on chromosome 15**.
- It's normal to have two copies of chromosome 15 - one from our mum and one from our dad
- **But in Ivor's case he has two paternal copies of chromosome 15 - meaning that there is one important gene called UBE3e that is not functioning as it should**
- This gene controls a protein involved in brain functioning that helps us walk, talk and perform many other everyday tasks.

# What are the symptoms of Angelman syndrome?

- People living with Angelman syndrome are significantly **intellectually suppressed** and typically have **balance issues, motor impairments** and can have debilitating **seizures**.
- **Disruptive sleep** is often a serious challenge.
- **Some never walk**. Most are **unable to speak** verbally.
- **Behavioural issues** are really challenging.
- And while not degenerative, individuals living with Angelman syndrome are currently unable to live independently and require continuous care throughout their life.

# Our decision

- Limited alternatives
- What was right for Ivor
- What was right for our family



# Why it works

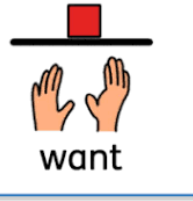
- Translation planning with our Local Authority
- Meetings with the school prior to starting
- Day to day school life
- Wider school and community



# Other Angelman experiences

## Top tips!

- Explain to the other children what non-verbal means. They can communicate, just not with words.



- Try to change the language.

E.g. instead of “hitting” (which means trying to hurt someone), say “excited/flapping/communicating/frustrated...”.

**Understanding intention can help to work out how best to support behaviour and attitudes towards it, for both teachers and children.**

# Challenges

- Twists, turns and hiccups
- How you deal with it, working together
- No instruction book



# Wish list

- Better external support
- After school clubs/holiday clubs
- Incentives and support for staff and carer careers
- Streamline services



# Feedback from teachers

- “It is so lovely to have your support and to be able to have this open communication between everyone who assists in Ivor’s learning journey and development.”
- “It is important that, as a teacher, we support the parents just as much as the child and we listen to their thoughts surrounding the child and to help guide them through the education system”



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- “One of the things that has worked really well is that we had open and honest correspondence with Ivor’s family right from the start. Sarah created a leaflet to show Ivor’s traits, what to expect and even some ideas on how to encourage him with learning. Sarah also did a talk for the school to help the whole school understand Ivor.”
- “Understanding Angelman syndrome has and always will be significant to us understanding Ivor. Ivor’s learning has always been centred around his interests as much as possible.”



# It can work

A success story!

Talk to us, include us, work together as a team.

Disabled children should not be shut away from the world.

They should be a part of it.

