

# Let me flourish

## What can be done better to support disabled children and their families in Wales



This document was written by **Care Inspectorate Wales (CIW)**. It is an easy read version of **Let Me Flourish: National Review of early help, care and support and transition for disabled children in Wales**.

**November 2021**

# How to use this document



This is an easy read document. But you may still need support to read it. Ask someone you know to help you.



Words in **bold blue writing** may be hard to understand. You can check what all the words in blue mean on **page 34**.



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# Contents

Introduction.....	4
The Review.....	6
Actions Needed.....	7
What we found out, and how we can make it better.....	10
Well-being.....	16
Partnership – Working Together.....	22
Prevention – Stopping things getting worse.....	26
Conclusion.....	31
What happens next.....	33
Hard words .....	34

# Introduction



Children need support to live a full and happy life.



Disabled children may need more support.



It is important for organisations and staff to work with families to make sure disabled children have the right support at the right time.



We carried out a review to check the experiences of disabled children and their families.



This document says what we found out about the support disabled children receive, and what works well and what could be done better.

## We wanted to know:



- how people receive information, advice and help



- about **assessments** and care and support plans



- how well disabled children and their families were supported.



An **assessment** is asking you questions and finding out about you. This helps to plan your support and understand what help you need.

# The Review

We carried out a review that looked at four main areas:

## People's voice and control

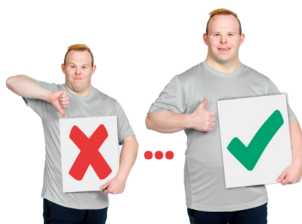
Do disabled children and their parents or carers have their voices heard?



And are they supported to make decisions about their lives?

## Stopping things getting worse

Do local authorities help to stop people's needs getting worse and needing more support?



## Well-being

Are local authorities helping disabled children and their parents or carers to have happy lives?



## Working together

Are local authorities working with other organisations and professionals to give a good service to disabled children and their parents or carers?



# Actions Needed

## Local Authorities

To make things better for disabled children and their families, local authorities need to:



- think about people's rights
- communicate better with disabled children
- listen to disabled children



- make sure they are following the law called the **Social Services and Well-being Act 2014**
- make sure professionals working with disabled children have the correct training



- make more opportunities to hear the thoughts of disabled children and their parents or carers
- make sure **accessible** information is given in good time



**Accessible** information is making sure information is given in a way more people can use it. For example in Easy Read.



- make sure the Welsh language is offered
- check and make sure services are good quality and information is recorded properly



- make sure professionals know about **safeguarding** disabled children

**Safeguarding** means keeping people safe from harm and abuse.



- make sure there are enough suitable services for disabled children in the local area



- include disabled children and their families when making decisions about moving into adult services

- make sure they follow the **Children and Young People's Continuing Care Guidance**. This is guidance from the Welsh Government. It helps to plan and support children's care needs.



- make more opportunities to work with other organisations to improve services



- follow the rules called the **Statutory Code of Practice on the Delivery of Autism Services** . These are rules about how autism services should work. And what services should be available.

## Local Health Boards



To make things better for disabled children and their families, local health boards (the local NHS) need to:

- check health services for disabled children to make sure there are enough health services available for disabled children
- make sure they follow the **Children and Young People's Continuing Care Guidance**.
- Make sure there are enough local placements for children who need them.



- make more opportunities to work in partnership with other organisations to improve services for disabled children



- follow the rules called the **Statutory Code of Practice on the Delivery of Autism Services**.

# What we found out and how we think it could be better

## People's voice and control

### What we found out:



There were some good examples that showed disabled children and their families were listened to.



Most parents and carers of disabled children felt that their social worker got to know them well.

### How we think it could be better:



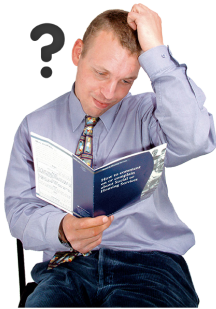
More time and opportunities should be given to **professionals** to get to know children better.



**Professionals** are the people working with disabled children and their families. For example social workers.



Local authorities and **professionals** should use different ways of communicating with different people, depending on their needs.



Professionals get lots of training but don't always get training specific to the needs of the child they are working with.

## What we found out:



There were good examples of parents, carers and **professionals** speaking up on behalf of disabled children.

We think **advocacy** is important.



An **advocate** is someone who speaks up for you to help you say what you want to say and get your needs met.

## How we think it could be better:



We think there should be more opportunities given for **advocates**.



This includes helping people be self-**advocates**. This means being able to speak up for yourself.



**Professionals** should know more about **advocates** and why they are important.

## What we found out:



The law called the **Social Services and Well-being Act 2014** says carers including parents of disabled children need to be offered the opportunity to have their needs **assessed** by local authorities.



There were some examples of carers needs being met. But there were many carers who had not had an **assessment**.

## How we think it could be better:



Local authorities must make sure carers are given their rights.



This includes making sure people know their rights.



**Professionals** must know what the law says about carer **assessments** and needs.



Local authorities should be better at keeping information about carers **assessments**.



Local authorities also need to be better at looking at why some carers might not want an **assessment**.



Local authorities and organisations need to check the support given to carers more often.

### **What we found out:**



There needs to be a list of disabled children. This list should be kept up to date.



Not every local authority had done this, even though it is the law.

### **How we think it could be better:**



Local authorities must make a list of disabled children in their area.



This list needs to be kept up to date. This will help local authorities plan services for disabled children.

## What we found out:



**Professionals** work hard to try to make sure disabled children have a good future.



**Professionals** enjoyed their jobs and felt supported by their bosses.



Sometimes it was hard for local authorities to hire more staff.

This is important because some families had different **professionals** who kept changing.

## How we think it could be better:



We think children and families should have the same **professionals** for as long as possible so that good relationships can be made.

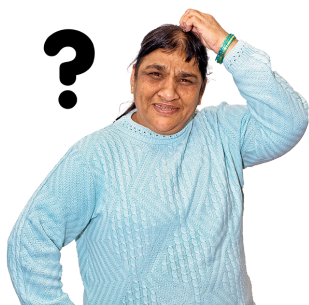
# Well-being

## What we found out:



Local authorities knew about **safeguarding** and took it seriously.

**Safeguarding** means keeping people safe from harm and abuse.



There were a few times where **safeguarding** concerns were not always fully recognised.



And the care and support plans did not make sure needs were fully met.

## How we think it could be better:



Local authorities must make sure **safeguarding** procedures for disabled children are as strong as they are for non-disabled children.



**Professionals** should know that disabled children may be at a bigger risk of abuse and neglect.

## What we found out:



Most parents and carers of disabled children valued the support they received.



But some felt they need to be given more information, advice and help.

## How we think it could be better:



We think local authorities and **professionals** can be even better at making sure disabled children and their families get the right information, advice and help.



We also think it is important that people should not have to wait for the information, advice or help.

## What we found out:



There were good examples of **assessments**, care and support plans being done well and including people's voice.



But we also think **assessments**, care and support plans can be made even better.

## How we think it could be better:



Local authorities need to make assessments and care and support plans look at people's strengths and focus on **outcomes**.

An **outcome** is like a goal. It is the result of what someone wants.



The **assessments** and care and support plans should follow the codes of practice. These are the rules for doing things the right way.



The **assessments**, care and support plans should be checked to make sure they are good quality.

## What we found out:



There were good examples of support being given to young carers and the brothers or sisters of disabled children.



But we think local authorities can do even more to help.



There are some brothers and sisters, and young carers who are waiting to get the support they need.

## How we think it could be better:



Local authorities should look at the support they give to young carers and the brothers or sisters of disabled children.



They should find out if more services are needed and look how they can create new services.

## What we found out:



**Direct payments** should be offered more, and more information needs to be given about it.

**Direct Payment** is money that social services can give to people instead of a service. The person can spend the money on getting the support and services they want. This gives people more control.

## How we think it could be better:



Local authorities need to make sure **direct payment** is included as an option when making assessments, care and support plans.



Local authorities need to make sure there is enough choice of services for disabled children and their parents or carers to decide to use **direct payment**.

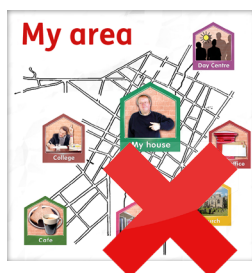


If people use **direct payment** then plans should be made about other care and support options in case of emergencies.

## What we found out:



There were good examples where disabled children in care were getting good support and having their voice heard.



But there were also times when disabled children were living outside of their local area.

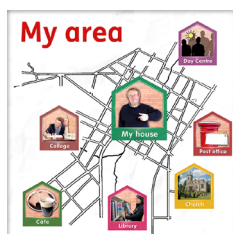


And also where they did not always get visits from **professionals** in good time.

## How we think it could be better:



We think local authorities must make sure disabled children are getting a good service in care.



Local authorities need to make sure more local care services are provided.



We also think there should be improvements to the planning for children for when they reach adulthood.

# Partnership – Working Together



It is important that local authorities, **professionals** and organisations work together and with disabled children and their parents and carers.

## What we found out:



There were some good examples of organisations, local authorities and **professionals** working together.

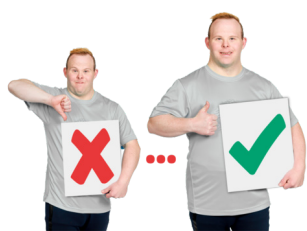


The best examples included **professionals** working with disabled children, parents and carers and families.



But there were some times when communication across these partnerships could be better.

## How we think it could be better:



We think local authorities, health boards and service providers can be even better at working together.



They should focus their work on the people they support and be **outcome** focused.

## What we found out:



The best examples of **transition** were when **professionals** worked together. And with disabled children and their parents and carers to plan well ahead for changes.

**Transition** means moving. In this example it means moving from children's services to adults services.



But some parents and carers said they felt the planning for their child's **transition** could have been better.

## How we think it could be better:



We think disabled children should be included in the planning for their future.



This includes information being given with enough time to think about it.



We think that more time should be given to planning the **transitions**.



There also needs to be more options for disabled children about where they live, and what they do with their time.

## What we found out:



Sometimes local authorities and health boards did not always agree on their responsibility for children who need continuing care.



The Welsh Government has written guidance about this in January 2020.

### **How we think it could be better:**



Local authorities and health boards need to make sure they know about and act on the guidance given by the Welsh Government about continuing care.

# Prevention – Stopping things getting worse

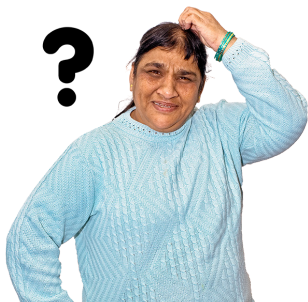
## What we found out:



If disabled children and their families or carers get support when they need it they can have better lives.



In some parts of Wales there were good examples of support being offered in time.



But some parents and carers felt confused about what help they could get.

## How we think it could be better:



We think support and help for disabled children and their families could be better if it is given at the right time.



Local authorities could improve the information they give and make it more **accessible**.

## What we found out:



Most parents or carers who received support said they valued the support.



But many said that their child needed more support.

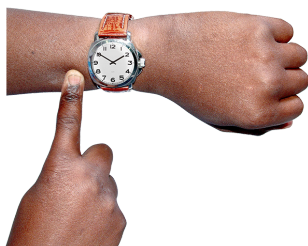


We also found out that some of the services offered to children and their families had long waiting lists.

## How we think it could be better:



We think local authorities and health boards should check the waiting lists more often.



This will help to make sure people's needs are not getting worse while they are waiting for a service.



We also think more services need to be made so that more people can get support when they need it.

## **What we found out:**



Sometimes disabled children and their families were asked about the services they would like to see and have received.



But more than half of the families said they had not been asked.

## **How we think it could be better:**



We think it is important that children and their families are asked about services.



Local authorities need to ask more people in the future when they are planning services.

## What we found out:



There were some good examples of how **assistive technology**, aids and adaptations were made to help disabled children.

**Assistive technology** are tools that help make life easier.



This means their homes were made more **accessible**, and equipment was provided to help disabled children be as independent as possible.



But we also found waiting lists for some equipment and adaptations. These waiting lists were being checked by local authorities.



An example of equipment and adaptations are ramps, handrails, or something that makes life easier.

## How we think it could be better:



Waiting times for occupational therapy needs to be made shorter.



Local authorities could do even better in thinking about how **assistive technology** can be used.

## What we found out:

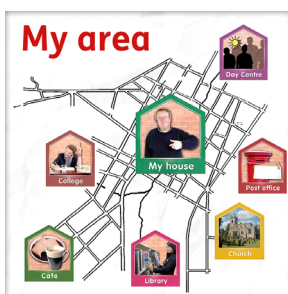


There were some good examples of play and community services.



Local authorities are trying hard to make sure there are enough sports and leisure opportunities for disabled children. But some parents thought there was not enough.

## How we think it could be better:

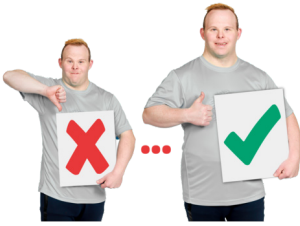


We think there needs to be more options available for disabled children and young people to do the things they like near to where they live.



We also think that children and their families should be asked what they would like to see in the area they live .

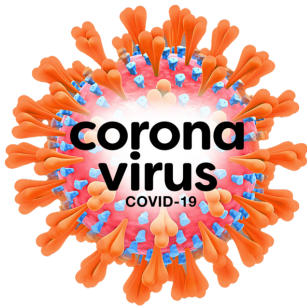
# Conclusion



We found out that local authorities and the organisations they work with really wanted to make things better for disabled children and their families.



They will need to make sure that people's rights are thought about when they plan services.



We know that the COVID-19 pandemic had a big impact on disabled children and their families.



The Welsh Government has written guidance on how people can be supported after the pandemic.



It is important that local authorities and the organisations they work with build on what has worked well during the pandemic and develop services for disabled children.



It is also important that local authorities and organisations listen to disabled children and their parents and carers.



This will help to make services better and more suitable.



And this will help to support disabled children to have a full and happy life.

# What happens next



We think local authorities, local health boards and organisations should think about this report.



It will help to make services in Wales better for disabled children and their families.



We will carry on looking at the services offered to disabled children and their families.

# Hard words

## Advocate

An advocate is someone who speaks up for you to help you say what you want to say and get your needs met.

## Assessment

An assessment is asking you questions and finding out about you. This helps to plan your support and understand what help you need.

## Assistive technology

These are tools that help make life easier.

## Direct Payment

This is money that social services can give to people instead of a service. The person can spend the money on getting the support and services they want. This gives people more control.

## Outcome

An outcome is like a goal. It is the result of what someone wants.

## Professionals

Are the people working with disabled children and their families. For example social workers.

## Safeguarding

This means keeping people safe from harm and abuse.

## Transition

This means moving. In this example it means moving from children's services to adults services.

