

**Changing**  
THE WAY WE  
*care*

**Toolkit for  
Disability  
Inclusion in  
Care Reform**

**PARTICIPATION & ADVOCACY**  
Half Day Learning Workshop



**USAID**  
FROM THE AMERICAN PEOPLE



MacArthur  
Foundation

# Child with a disability or a disabled child?

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- Human rights and development context favours 'person-first' language = **child with a disability, children with disabilities**
- Some activists prefer to acknowledge the social model and the barriers which inhibit full participation = **disabled child, disabled children**
- Don't assume you know best!
- **ASK** and use the terminology preferred by disabled persons organisations in your country

# By the end of this workshop you will...

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- ...understand the benefits of children's participation and family involvement
- ...have increased knowledge and awareness of self-advocacy approaches
- ...have generated ideas for introducing this learning in your program



*"We had a chance to tell the adults our opinion, they heard our voices."*

*"I sang in front of everyone, which I had never done before."*

*"Give us a chance to share our dreams, hopes and problems."*

*"Meetings with new and old friends."*

*"I had a chance to talk about my dreams, getting a job, friendship, doctors and what is good or bad for me."*

*"I rode a bicycle with my friend and after that we discussed children's rights!"*

*"We learnt not to argue in a bad way, and how to work together."*

*"It helped me to become useful for myself and also for others. I got brave, more confident, and I started to feel that people are listening to what I have to say. I became a thoughtful and more independent person who is able to analyse things. The project opened a door to for us to achieve more in our lives."*

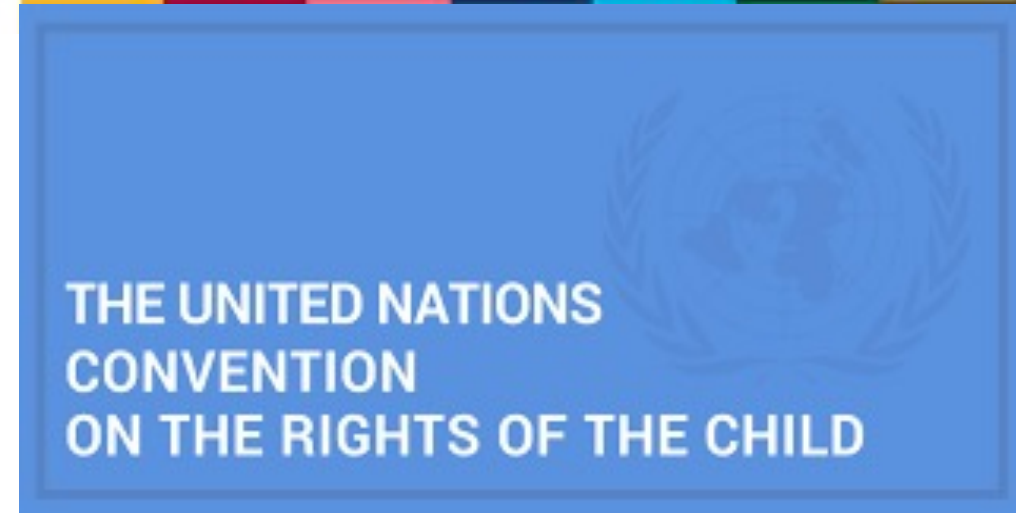
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## What children say about participation...



# What is participation?

- Article 12 of the UNCRC says that children and young people have the human right to have opinions and for these opinions to matter
- Article 12 applies everywhere and to everyone
- Its about being able to speak up – even if you have a different opinion from other people, or want to complain
- Its also a child's right to refuse to give an opinion

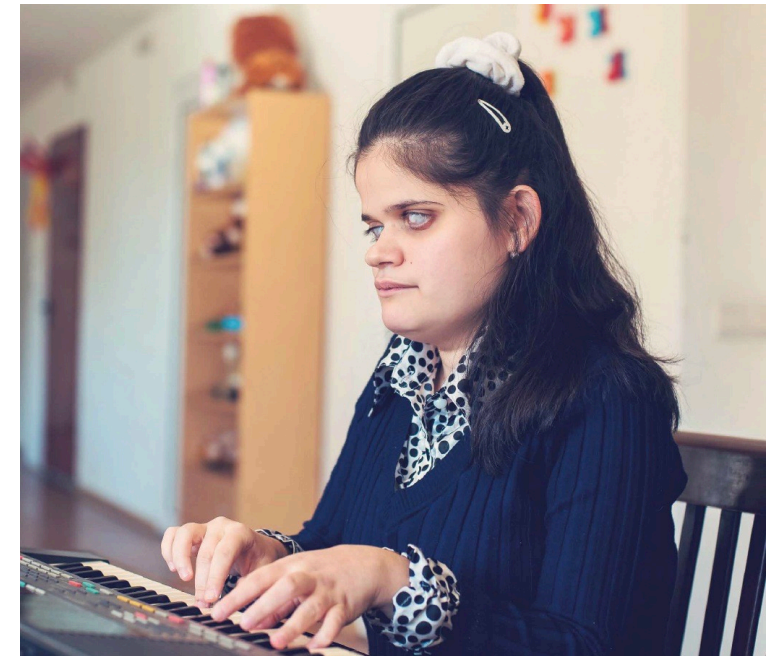


# What does the UNCRPD say about the right to participate?

**Article 21** Saying what you want and access to information

**Article 29** Being involved in politics

**Article 30** Being involved in sport and leisure



# What is advocacy?

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**Advocacy** is a process of supporting and enabling people to:

- Express their views and concerns
- Access information and services
- Defend and promote their rights and responsibilities
- Explore choices and options

**Advocacy** is when you get support to have your say



# An advocate will...

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**Talk** with a child with a disability to find out what they want

**Listen** to what the child has to say

**Find information** to help the child to make choices

**Talk to other people** or groups on behalf of the child (with their permission)

**Help the child say what they think** about their reintegration process, or any other issue that is important to them

A **self-advocate** is a child or person with a disability who is supported to speak for themselves

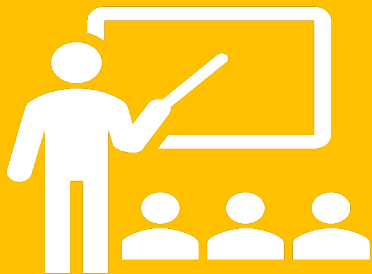




**Participation** is a human right!



**Advocacy** is the support provided for children with disabilities and their families to realize that right!



**Self-advocacy** is when a child has the skills, knowledge and support to advocate on their own behalf.



# Why is involving children & their families important?

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- ✓ Because it is their right
- ✓ Because services will be improved, better informed, better targeted and more effective
- ✓ Because projects will be on the right track from the beginning
- ✓ Because it is best practice



**Henry**



**Irina**



**Daniela**

# Henry and Daniela as self-advocates

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Daniela meets new friends who help her campaign to get access to the book



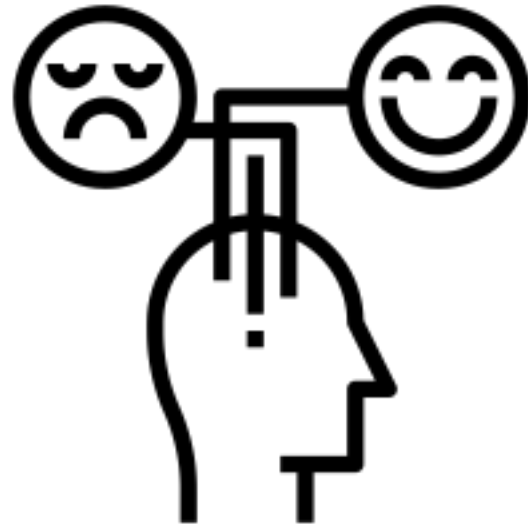
Henry meets new friends who help him campaign to join the youth club





# Participation can be hard...

- It is not culturally appropriate for children to speak up
- Children are discriminated against, for example in some countries girls are discouraged from speaking up
- Adults believe they cannot participate like other children because they have a disability
- Children with profound or multiple disabilities which significantly affect their capacity to communicate



# The Advocacy Charter

**CLARITY OF PURPOSE** Advocacy Providers ensure that the individuals they advocate for, referrers, health and social care services and funding agencies all receive information that helps them understand the advocacy service and the role of the advocate, including its benefits and boundaries. The Advocacy Providers objectives and activities must align with the principles set out in this Charter:

**INDEPENDENCE** The Advocacy Provider is independent from statutory organisations and all other service delivery and is free from conflict of interest, both in design and operation of advocacy services. The Advocacy Provider's culture supports Advocates to promote their independence with individuals, professionals and other stakeholders; Advocates will be free from influence and conflict of interest so that they can represent the person for whom they advocate.

**CONFIDENTIALITY** Information held by the advocacy service about individuals will be kept confidential to the advocacy service. The Advocacy Provider will have a Confidentiality Policy that reflects current legislation. It will be clear about how personal information held by the Advocacy Provider will be kept confidential, under what circumstances it may be shared, the organisation's approach to confidentiality in the delivery of Non-Instructed Advocacy and how the organisation responds if confidentiality is breached. Advocates will ensure that information concerning the people they advocate for is shared with these individuals unless there are exceptional circumstances, when a clear explanation will be recorded. Advocates must also be aware of situations that require making a child or adult safeguarding alert.

**PERSON LED** The Advocacy Provider and Advocates will put the people they advocate for first, ensuring that they are directed by their wishes and interests. Advocates will be non-judgmental and respectful of people's needs, views, culture and experiences.

**EMPOWERMENT** The Advocacy Provider will support people to self-advocate as far as possible, creating and supporting opportunities for self-advocacy, empowerment and enablement. Advocates support people to access information to exercise choice and control in their lives and the decisions affecting them. People will choose their own level of involvement and the style of advocacy support they want. Where people lack capacity to influence the service, the Advocacy Provider will ensure the advocacy remains person led and enable those with an interest in the welfare of the person to be involved. People receiving advocacy will be involved in the wider activities of the organisation up to and including the Board.

**EQUALITY AND DIVERSITY** The Advocacy Provider will have an up to date Equality and Diversity Policy that recognises the need to be pro-active in tackling all forms of inequality, discrimination and social exclusion so that all people are treated fairly. Advocates time will be allocated equitably. Advocates make reasonable adjustments to ensure people have appropriate opportunity to engage, direct and benefit from the advocacy activity.

**ACCESSIBILITY** Advocacy will be provided free of charge to eligible people. The Advocacy Provider will ensure that its premises (where appropriate), policies, procedures and publicity materials promote full access for the population that it serves. Advocates will provide information and use language that is easy to understand and accessible to the person.

**ACCOUNTABILITY** The Advocacy Provider is well managed, with appropriate governance arrangements in place, meeting its obligations as a legally constituted organisation. People accessing the service will have a named Advocate and a means of contacting them. The Advocacy Provider will have systems in place for effective recording, monitoring and evaluation of its work, including identification of the impact of the advocacy service and outcomes for people supported. In addition, it will be accountable to people who use its services by obtaining and responding to feedback and complaints. The Advocacy Provider will address systemic issues in health and social care provision or other services.

**SAFEGUARDING** As part of supporting people to realise their Human Rights, the Advocacy Provider will have a thorough understanding of safeguarding responsibilities and processes as set out in law and best practice guidance. The Advocacy Provider will have clear, up to date policies and procedures in place to ensure safeguarding issues are identified and acted upon. Advocates support people to have their rights upheld and will be supported to understand and recognise different forms of abuse and neglect, issues relating to confidentiality and what to do if they suspect an individual is at risk.

**SUPPORTING ADVOCATES** The Advocacy Provider will ensure that Advocates are suitably trained, supported and supervised in their role and provided with opportunities to develop their knowledge, skills and experience, including access to legal advice where necessary. It will create a supportive culture that enables Advocates to undertake their role in line with this Charter.

Advocacy is taking action to support people to say what they want, secure their rights, pursue their interests and obtain services they need.

Advocacy providers and Advocates work in partnership with the people they support and take their side, promoting social inclusion, equality and social justice.



National Development Team for Inclusion

# The Advocacy Charter

for Advocacy Providers

Advocacy helps you to have your say in what happens in your life.  
Advocacy is supporting you in speaking out about your rights, what you need and what is important to you.

**Clarity of Purpose**  
This means we will be clear and honest about what we can and cannot do for you.

**Independence**  
We are separate from other services and will help you ask for things that are important to you.

**Confidentiality**  
We will keep information about you private and safe. If we need to share information, to keep you or other people safe, we will try to talk to you first.

**Person Led**  
We will ask you what you want to happen, and give you information to make choices.

**Empowerment**  
We will help you to speak up for yourself.

**Equality and Diversity**  
We will treat all people fairly and with respect and make sure other people do too. We will make sure you get the support you need to have an advocate and will change things for you if you need us to. We will make sure other people treat you fairly and with respect.

**Accessibility**  
Our services are free. We will use words you can understand. We will make sure you can see your advocate in a place that is good for you.

**Safeguarding**  
We will make sure advocates know about your rights and how to help you stay safe.

**Accountability**  
We will check what we do for you, and ask you what you think.

**Supporting Advocates**  
We will help and support advocates to be good at their job. That way they can help you to speak out



~~IMPOSSIBLE~~



- ✓ Make participation part of the program
- ✓ Develop individual participation plans
- ✓ Become an advocate
- ✓ Support others to participate & advocate
- ✓ Learn more

# Changing THE WAY WE care

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**Need to know more?** Contact Changing the Way We Care at [info@ctwwc.org](mailto:info@ctwwc.org) or visit [changingthewaywecare.org](http://changingthewaywecare.org)

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