

Focus on Disabilities & Illnesses

North Wales
Regional Innovation Coordination Hub

www.northwalescollaborative.wales

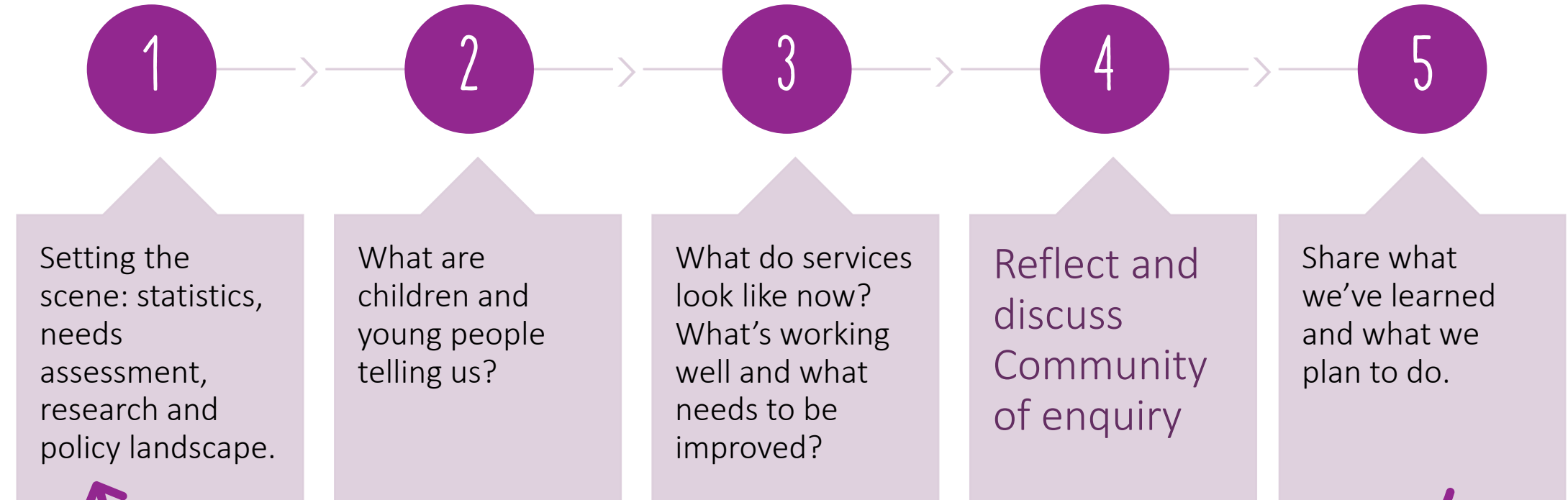
March 2023

Agenda

1. The plan
2. About the topic
3. What we found out
4. Community of enquiry
5. Action plan

The plan

Today



Children and young people and organisations who support them

About the topic:

- The definition of children and young people with disabilities and/or illnesses is broad.
- There is no full register of disability or ill-health.

What we found out

Respite care gaps in North Wales:

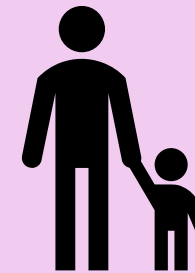
- Limited local accommodation for children with complex needs.
- Not enough respite accommodation in most regions.
- Not enough short break foster carers with specialist skills.

**North Wales Together:
Seamless Service for People with Learning Disabilities**



6,440

Disability Living Allowance (DLA) child claimants in North Wales (2022 estimate)



660

disabled children were receiving care and support from social services in North Wales (2021 statistics)

“I am beyond exhausted. I’ve had to leave my specialist nurse job of 23 years to become my daughter’s full-time carer, as there’s no support for her”.

Parent quote from the Population Needs Assessment 2022

Amser Ni

Amser Ni is a project in Gwynedd and Anglesey that provides short breaks for children and young people with disabilities and illnesses.

Amser Ni prefers the term 'short breaks' over 'respite care' because it sounds more positive and doesn't have the negative connotations of the child sounding like a burden.

There is a case study from Amser Ni within the Toolkit

Amser Ni case study

A 14 year old boy was referred to Amser Ni. He's diagnosed autism with associated learning difficulties, and he also has a recent diagnosis of type 1 diabetes. He lives with his parents and older sister. Following the diagnosis of diabetes, caring for him and his medical needs increased and due to unstable sugar levels, his parents were having to be up during the night also. He was becoming isolated at home and refusing to go out for his parents. His family were struggling and wanted to access respite care support. His parents found it very difficult caring for him and also felt extremely guilty that they were not able to spend quality time with his sister due to always concentrating on caring for their son.

The boy has settled well in the foster carers' home. He is happy and he has a good relationship with both foster carers. During his stay he has 1-1 attention which has encouraged him to develop new skills. He's learning how to shop for food and how to cook and clean up after himself. He is also able to have experiences that he wouldn't be able to have at home such as local outdoor walks, visiting the beach, swimming, and going to the cinema.

The young boy is able to spend quality time with his foster carer and gain new experiences and his family are able to rest and recharge through having a break from their caring role which will enable them to continue caring for him in the future. The young boy will continue to be offered a regular short break of one weekend every 6 weeks.

Lessons from elsewhere

Shared Care Scotland (2022) is a collection of good practice short breaks and respite care examples.

Carers Trust has a vision of short breaks for children and young people with disabilities and illnesses.

The Council for Disabled Children explored short breaks and selected key learning examples.

Intervention alongside short breaks to support parents may be beneficial.

Videos created by 'Respitality' as good practice examples.

Roseann's story

(45 secs)



What is Respitality?

(1:28 animation)



Community of enquiry

Respite care for children and young people
with disabilities and/or illnesses.