



Integrated Care Matters Webinar Series 7 Child and Family Centred Approaches

April 19th

111 people from 27 countries registered for this webinar on Child and Family Centred Approaches



Cara English, CEO, Cummings Graduate Institute for Behavioural Health Studies (CGI) and **Marianne Tyler, Senior Development Officer, Health and Social Care Alliance Scotland** Children and Young People Programme, welcomed our Panellists and invited them to share their insights and experience.

Anders Olauson, Honorary President European Patients' Forum and Chair of the the **Agrenska** Foundation, Sweden, spoke of the complexity that many families face trying to navigate services from healthcare, education, social care, employment and funding bodies. Efforts are not coordinated and patients, parents and siblings need peer support from people with lived experience. This challenging reality has inspired a global movement to support people affected by Rare Diseases. Anders outlined the valuable support for families provided by Agrenska since 1989 and gave us a glimpse of what we can expect in future.

Dorica Dan, Coordinator of the **NoRo Centre** in Romania described their journey to establish a centre of expertise and resources for rare diseases. It is based on intersectoral partnerships that have a person-centred, multidisciplinary, continuous and participative approach and builds community capacity for family centred case management through telementoring training and education. The Centre shares best practice through inclusive learning opportunities and is an important source of advocacy for designing, implementing and monitoring policies and services at local, national and international levels.

Karsten R. Barton, Physiotherapist and **Lisen Julie Mohr**, Senior Communications Advisor **Frambu Resource Centre for Rare Disorders**, spoke about the low threshold, holistic interdisciplinary services provided for patients, their families and local/regional professionals and providers. The goal is to develop, collect and spread knowledge and expertise related to Rare diagnoses /disorders and to create a bridge between patients and families and various stakeholders providing health care, social care and social support. Their online resources can be translated to any language: <https://frambu.no/>

Marianne Tyler, presented Scotland's Getting it right for every Child approach (GIRFEC). This is for all children, not just those living with rare diseases. It places the child or young person and their family at the heart, and promotes choice and participation in decisions that affect them; working together with families to enable a rights-respecting, strengths-based, inclusive approach.

"We need to ensure that all work puts patients (people with lived experience) at the heart of services".

Take Home Messages

We are working for a world where no one is left behind!



Don't forget to include patients at all levels!

- ⇒ "In order to understand how it is to be a parent to a disabled child – you have to be a parent to a disabled child yourself!"
- ⇒ International cooperation and partnership across organizations serving similar populations.
- ⇒ Ongoing leadership of patients and parents to ensure inclusivity and respect for rights and preferences.
- ⇒ Advocacy for legislative action to enable system and service changes as well as advocacy for needed services.
- ⇒ Better education and training for providers and families to improve health literacy and care outcomes.

"An integrated approach that would minimise barriers"


We need to look at the whole picture, wider than just health which includes families and communities.

You will find the webinar recording [here](#) and Presentation slides [here](#)

Register for our next Webinar:

[Personalising Population Health](#)

June 14th @ 4.00 - 5.30 pm BST

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