

How Sweden and the Big5 have inspired the holistic approach to the needs of people living with a rare disease and their families

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ÅGRENKA



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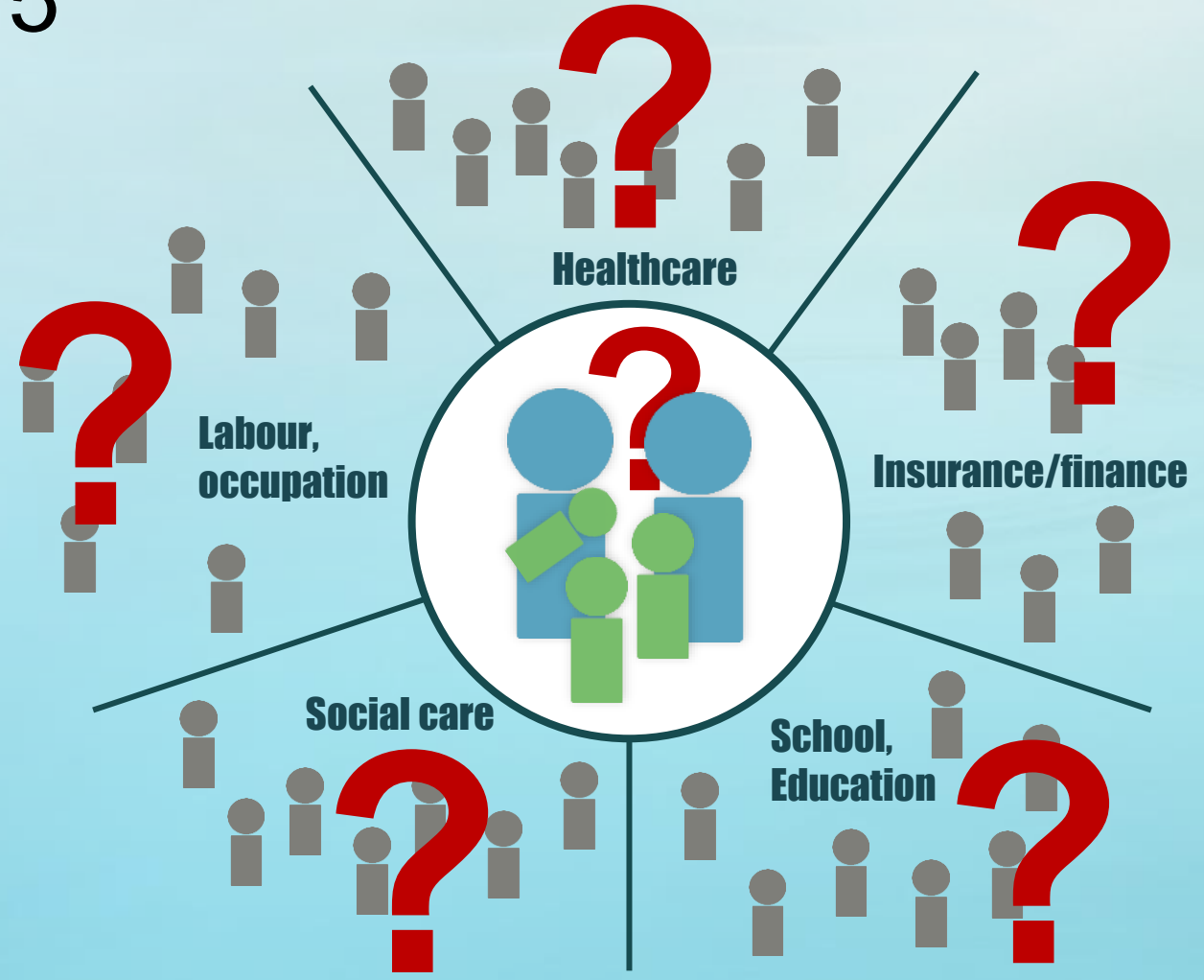


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Having a child.....



The reality for families is from 40 to 120 contacts with the Big 5



Today's Ågrenska started by combine the following parties;

- Hospital,
- School,
- Social,
- Patients
- the Agrenska Foundation





Anders Olauson founder of Ågrenska -

H.M. Drottning Silvia Patron of Ågrenska



Agrenska programs 1989 - 2023

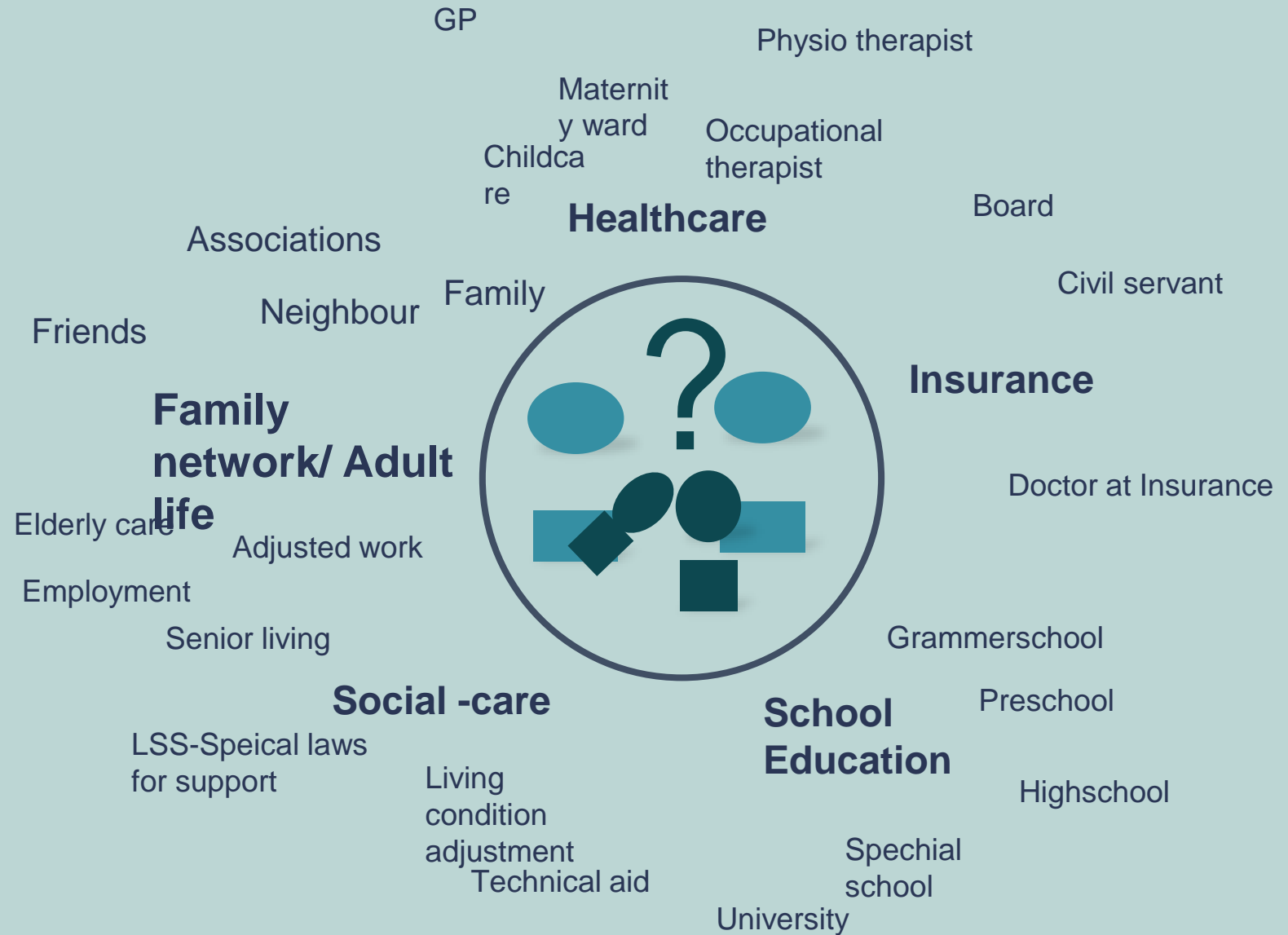
- **Family program** – focus on rare diseases, since 1989 >5 000 families
- **Adult program** – focus on rare diseases
- **Respite care** - all kinds of disabilities
- **Staff with disabilities** – day centre
- **Personal assistance**
- **ADHD/NPF** consultant
- **Courses for professionals**
- **Research**
- **Conferences**
- **Projects/development**



Queen Silvia Patron of Agrenska Sweden

What is **Rare Diseases**

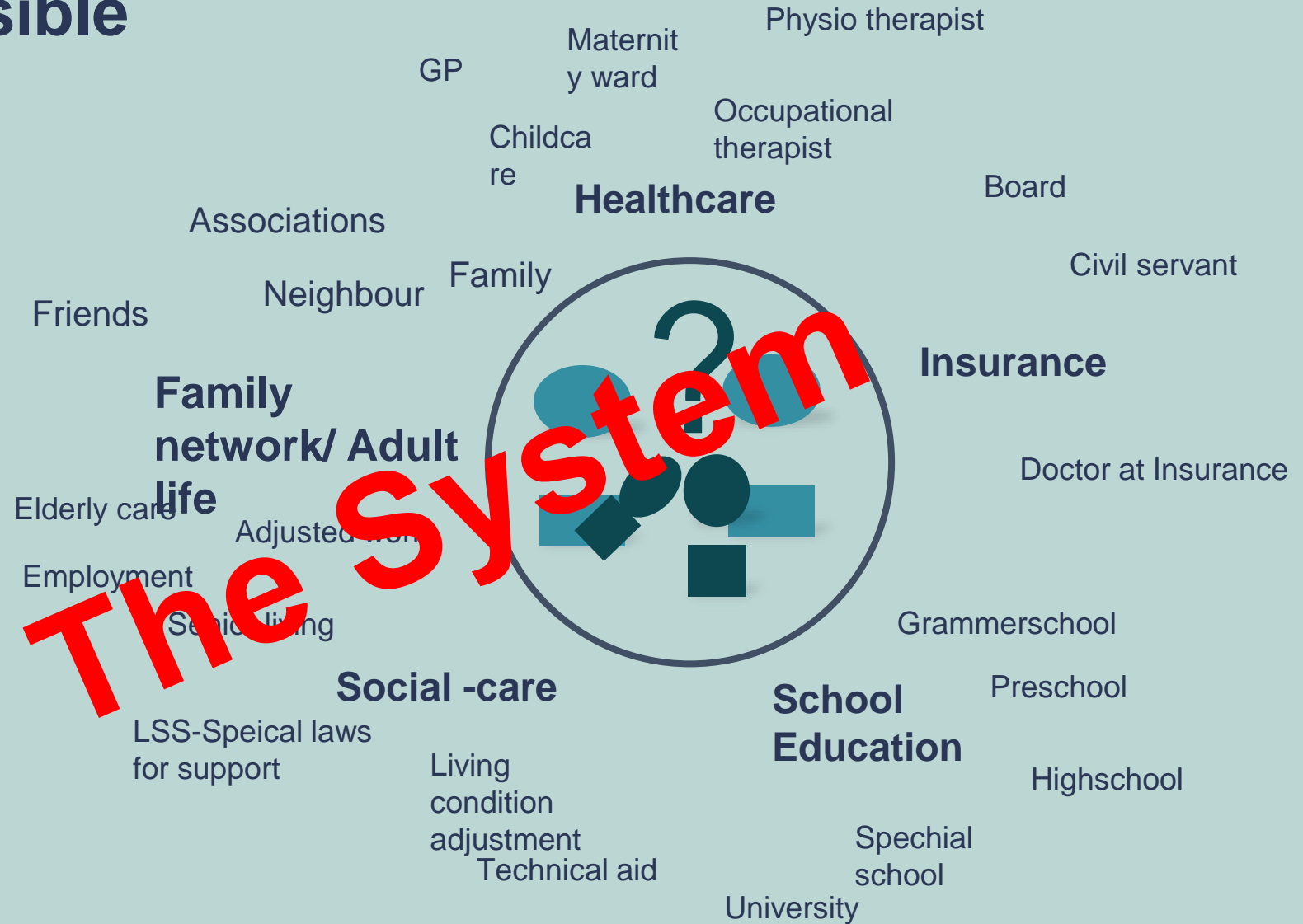
40-120
contacts



Who is responsible

Rare Diseases

40-120 contacts



Having a child.....



Why patients view, -Some reflections after more than 30 year's of experience from Agrenska program

1. Too few professionals have knowledge of rare diseases and their impact on individual and family
2. Efforts incomplete or wrong
3. Long time before diagnosis set - needless suffering
4. Charged to the wrong parts of the system
5. Society's efforts are not coordinated - system competence is lacking in many of society - must be a carrier of knowledge
6. Need to discuss opportunities instead of obstacles
7. Must always explain and "defend" their difficulties / disability due to rarity and ambient ignorance
8. Need different stages of life to gain knowledge and meet others in the same situation



A possible shift of paradigm in Sverige 1997?-2023?

In order to find out if there is any difference between families who have children with the same diagnosis, but who receive different interventions, Ågrenska, together with the university and the business school, carried out a sub-study in a larger project.

Families (X) who were allowed to participate in a family stay at Ågrenska were compared with families (Y) who received the ordinary contributions from society. These families had children with the same diagnosis.

This was done for several different diagnoses.

The families were asked partly at the starting point and partly 12 months later.

The result showed that the families in group Y spent health costs of SEK 35,000. per year, while those in group X spent SEK 13,500.

This means that in Sweden alone you can save approx. SEK 3,500,000,000 per year.

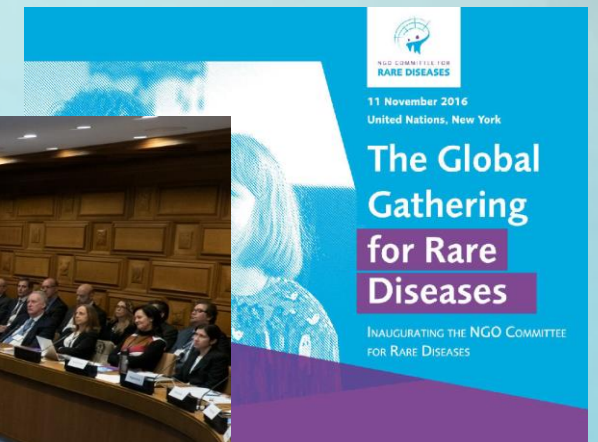


Committee for Rare Diseases

- At an initiative by Ågrenska and EURORDIS and RDI
- Inauguration 2016
- Events under 2018
- Event in NY at the UN 2019
- RD in the 17 SDGs
- UN Resolution in 2021



NGO COMMITTEE FOR
RARE DISEASES



Launch of NGO Committee



NGO COMMITTEE FOR
RARE DISEASES

11 November 2016

United Nations, New York

The Global Gathering for Rare Diseases

INAUGURATING THE NGO COMMITTEE
FOR RARE DISEASES



High Level Global Gathering UN Headquarters, New York



November 2016 / February 2022



Seventy-sixth session
Third Committee
Agenda item 28
Social development

Brazil, Central African Republic, Equatorial Guinea, France, Italy, Portugal,
Qatar and Spain: draft resolution

Addressing the challenges of persons living with a rare disease and their families

The General Assembly,

Recalling the Universal Declaration of Human Rights,¹ the International Covenant on Economic, Social and Cultural Rights,² the Convention on the Elimination of All Forms of Discrimination against Women,³ the Convention on the Rights of the Child,⁴ the Convention on the Rights of Persons with Disabilities⁵ and the Constitution of the World Health Organization,⁶

Reaffirming its resolution 70/1 of 25 September 2015, entitled “Transforming our world: the 2030 Agenda for Sustainable Development”, in which it adopted a wide, far-reaching, and people-centred set of universal Sustainable Development Goals and targets, and its commitment for the full implementation of the Agenda by 2030, ensuring

Taking note of the reports of the first and second High Level Panel of Experts, the High Level Panel of Experts on Rare Diseases, held at United Nations Headquarters on 11 November 2016 and 21 February 2019,

Recognizing the need to promote and protect the human rights of persons living with a rare disease, including the estimated 300 million persons living with a rare disease, many of whom are children, by ensuring equal opportunities to realize their developmental potential and to participate in society,

Reaffirming the right of every human being, without discrimination, to the enjoyment of the highest attainable standard of physical and mental health,

¹ Resolution 217 A (III).

² See resolution 2200 A (XXI), annex.

³ United Nations, *Treaty Series*, vol. 1249, No. 20378.

⁴ *Ibid.*, vol. 1577, No. 27531.

⁵ *Ibid.*, vol. 2515, No. 44910.

⁶ *Ibid.*, vol. 14, No. 221.



Redesigning health in Europe for 2020



World Health Organization



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living
and

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Challenges...

- 7 000 diseases,
- 150 orphan drugs
- Same need globally – different strategies
- Strong and sustainable patient's organisation..
- ERN-open up
- A sustainable socio-economic structure – cross budgetary system G20 in 2019 - onwards
- Increase interest from the research society for RD and not only Orphan Drug but also the other legs in the Big5
- EURORDIS work on mental health is inspiring, and also the work Agrenska is doing on pedagogical implications on rare diseases.
- Real life outcome and Patient reported outcome. We have to increase the confidence for this.
- EUPATI is one way to show how patients can be equal important to research and EURORDIS Academy as well.

How would healthcare look like in 2040,

- New drugs
- Nano-technology
- Medtech
- Lifestyle
- Nutrition
- Environmental situation, climate houses, food and work.
- Without the true information from patients knowledge and experience; the supporting companies and authorities will get lost

Thank you 😊



ÅGRENSKA



NGO COMMITTEE FOR
RARE DISEASES



SDGs and Rare Diseases – Synergies

Rare Diseases Challenges

Negative cycle of vulnerability and poverty due to exclusion from health and education systems and labor markets.

Universal health coverage = more and better drugs, appropriate diagnosis and lifelong care and social support.

50% of the rare diseases affect children who often face difficulties in their school due to physical inaccessibility and lack of appropriate teaching methods.

SDGs



SDGs and Rare Diseases – Synergies

Rare Diseases Challenges

Gender equality = recognition and evaluation of unpaid care and housework that many mothers of children (including adults) with rare diseases perform.

People with rare diseases and disabilities are often marginalized from the labor market due to lack of physical availability, flexible working hours and custom roles.

Need to invest in research and development of therapies, health technology and diagnostic methods. Access to infrastructure is the key to being included in society

SDGs



SDGs and Rare Diseases – Synergies

Rare Diseases Challenges

Marginalized and invisible people who are discriminated against in the areas: health, work and self-esteem over their everyday life

Rare community diagnoses are increasingly interconnected, with a multitude of patient advocates, regulators, research and industry networks.

The NGO Rare Disease Committee, CfRD, embraces these goals, as multi-stakeholder partnerships are anchored in the statutes.

SDGs

