

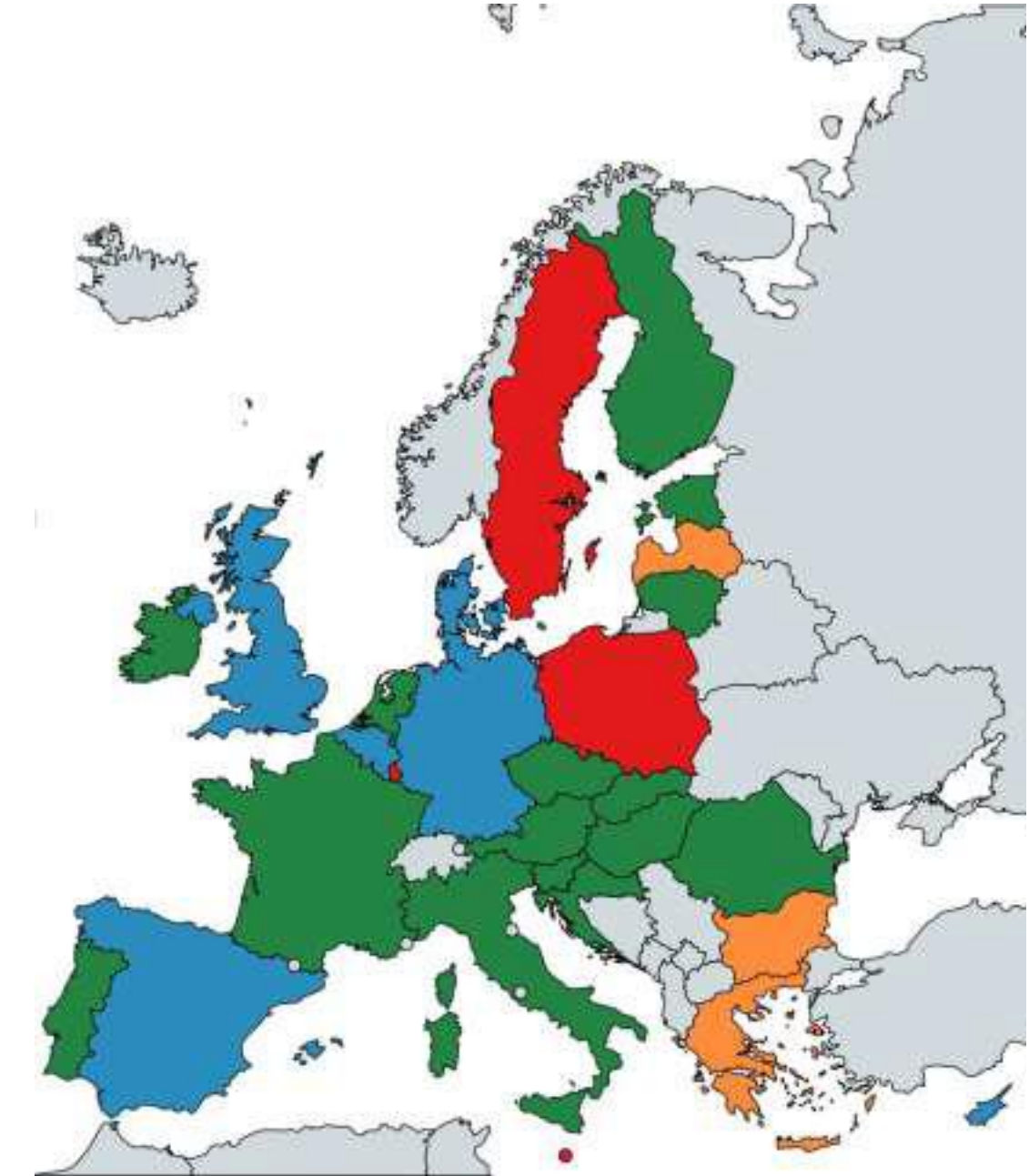
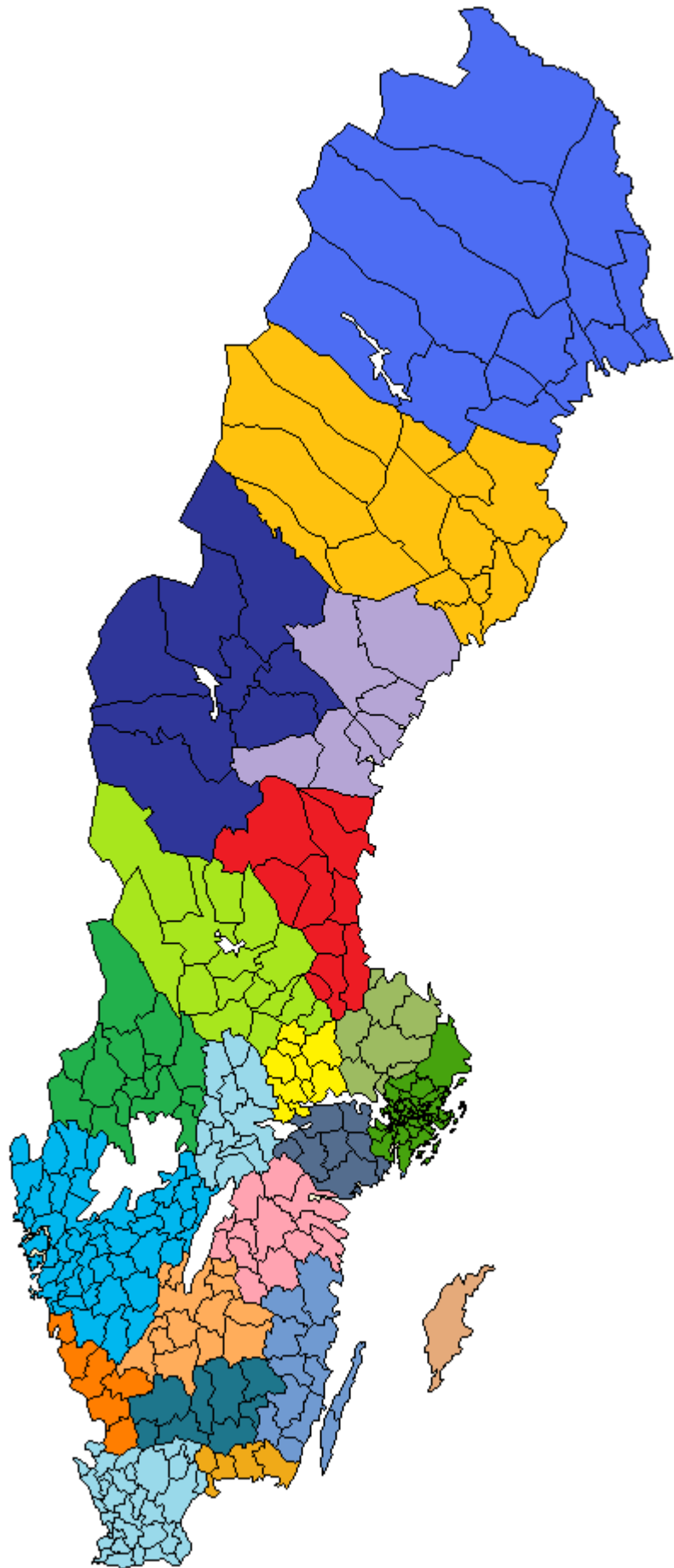
Rare healthcare transition model

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Sweden

- A large country with few inhabitants and 21 county councils
- Third largest country in the EU (450 295 km²)
- 22 inhabitants per km² (10.2 mill people)
- One of the last 4 EU-countries without national plan for rare diseases





Rare Diseases in Sweden

- 1 in 10 000 people
- Roughly 5% of Sweden's population is assumed to have a rare disease
- 30 mill in Europe, 350 mill all over the world



National alliance - Rare Diseases Sweden

More than 15.000 members from 65 patient organizations

Complex syndrome diagnoses (multi-disciplinary, healthcare system lacks expertise, often miss-/undiagnosed)

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DIAGNOSER**
RARE DISEASES SWEDEN

Transition to adult healthcare – member voices



Adolescents with rare diseases:

- Longing for independence
- Need to talk to independent third party individual



Adolescent with PKU:

- Child care until age of 20
- Who are my contacts now?
- Are there PKU experts?
- How to contact them?
- With whom to discuss sensitive matters?



Their parents:

Loss of knowledge

- In the healthcare system
- Among parents

Development of transition tools:

STEP 1

Understanding
the problem

STEP 3

Alphapilot real-world
test with 8 patients in
the healthcare
system



STEP 2

Transition-experiences;
how it was and how we
want it

Finding tools to
improve the transition

Develop and test
prototypes

Toolbox:



Transition - coordinator

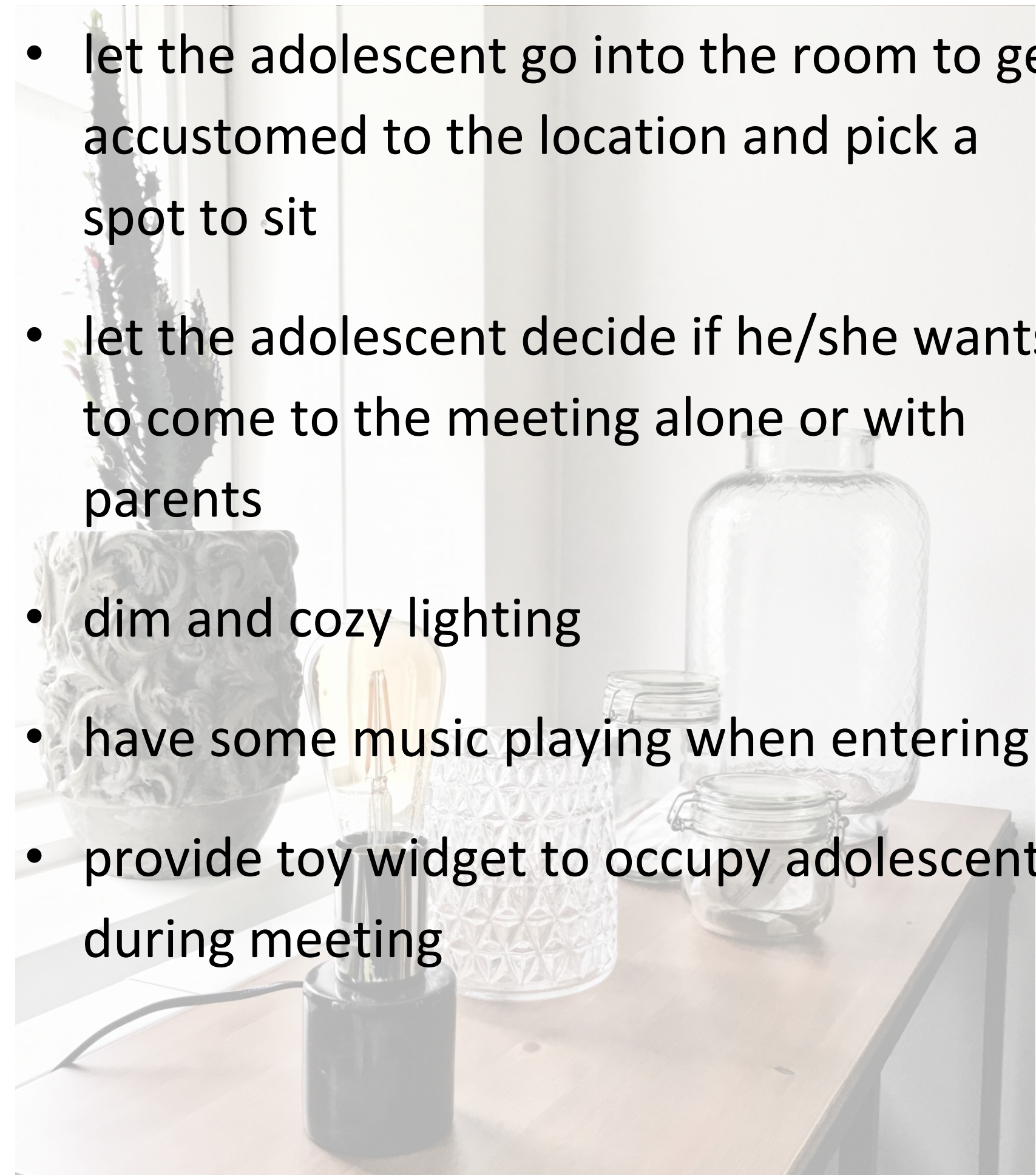
- e.g. nurse or healthcare counselor
- several meetings during transition
- knows the healthcare system and the different professions involved
- knows how to identify and get help from the right persons
- insightful and with good counseling skills
- knowledgeable about living with a rare disease
- experienced in and open for searching information from a wide variety of areas, following the adolescents' needs

Toolbox:

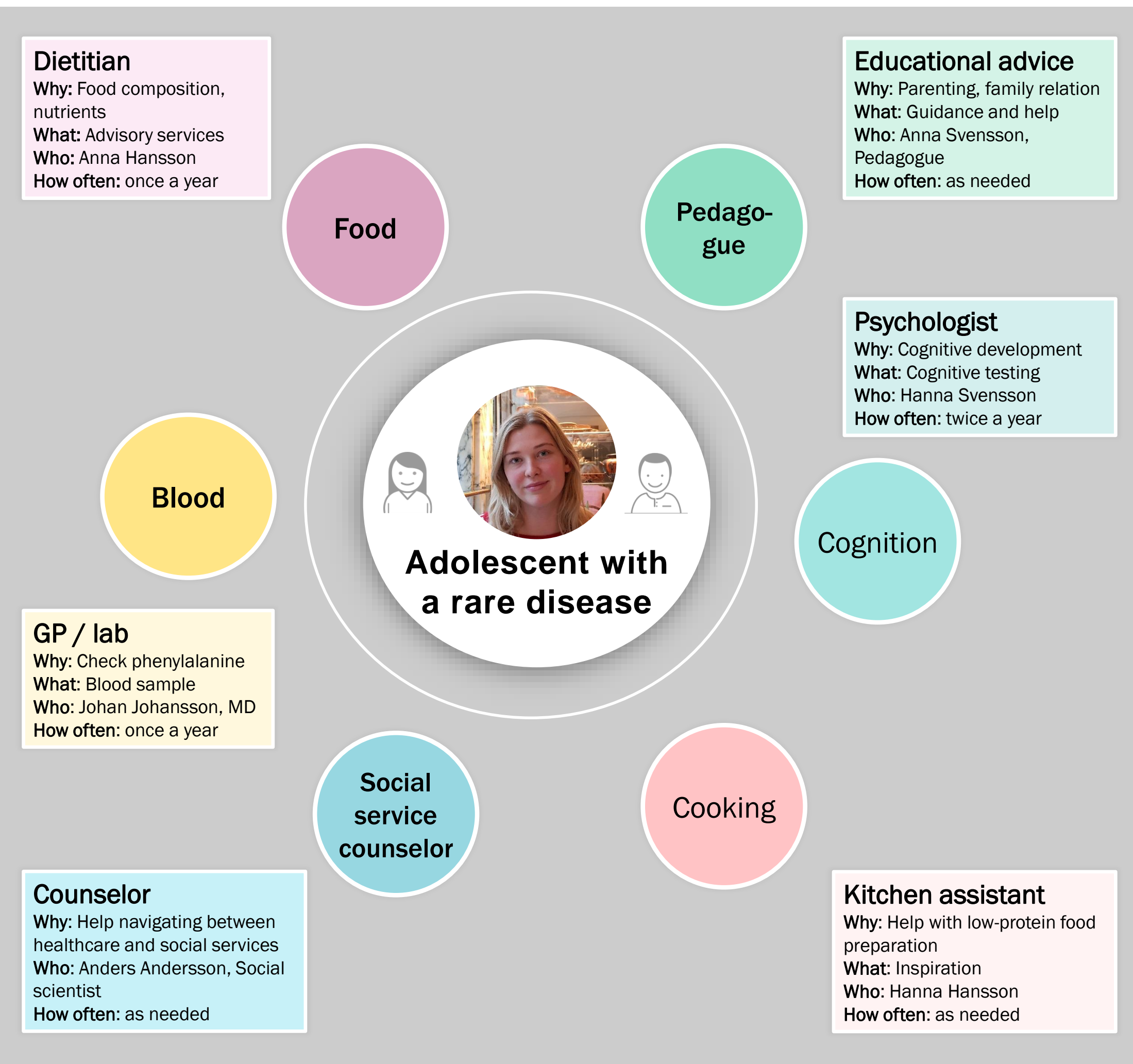


Transition room

- let the adolescent go into the room to get accustomed to the location and pick a spot to sit
- let the adolescent decide if he/she wants to come to the meeting alone or with parents
- dim and cozy lighting
- have some music playing when entering
- provide toy widget to occupy adolescent during meeting



Toolbox:



Care map

- visualisation of all healthcare contacts and their function
- possibility to group/organize all contacts if required
- aids in understanding of who does what among the healthcare contacts
- makes it easy to "replace" pediatric with adult healthcare contacts
- gives opportunity to talk about diagnosis and its consequences: Where? What for? Who? How often?
- our vision: develop a digital version

Toolbox:



Conversation cards

Grouped in four categories:

- my healthcare
- my life
- people who support me
- my diagnosis

Adolescent gets the opportunity to talk about diagnose-related questions but also worries about the future.

Alphapilot

Alphapilot, August - December 2017



Center for rare disease
Linköping
University hospital



1 transition coordinator
With transition tools
and cozy room



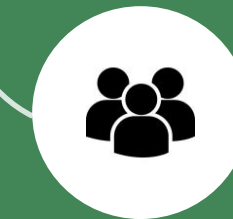
4 adolescents with a
rare disease about to
transit from child to
adult healthcare and
one parent



Center for rare disease
Karolinska
University hospital

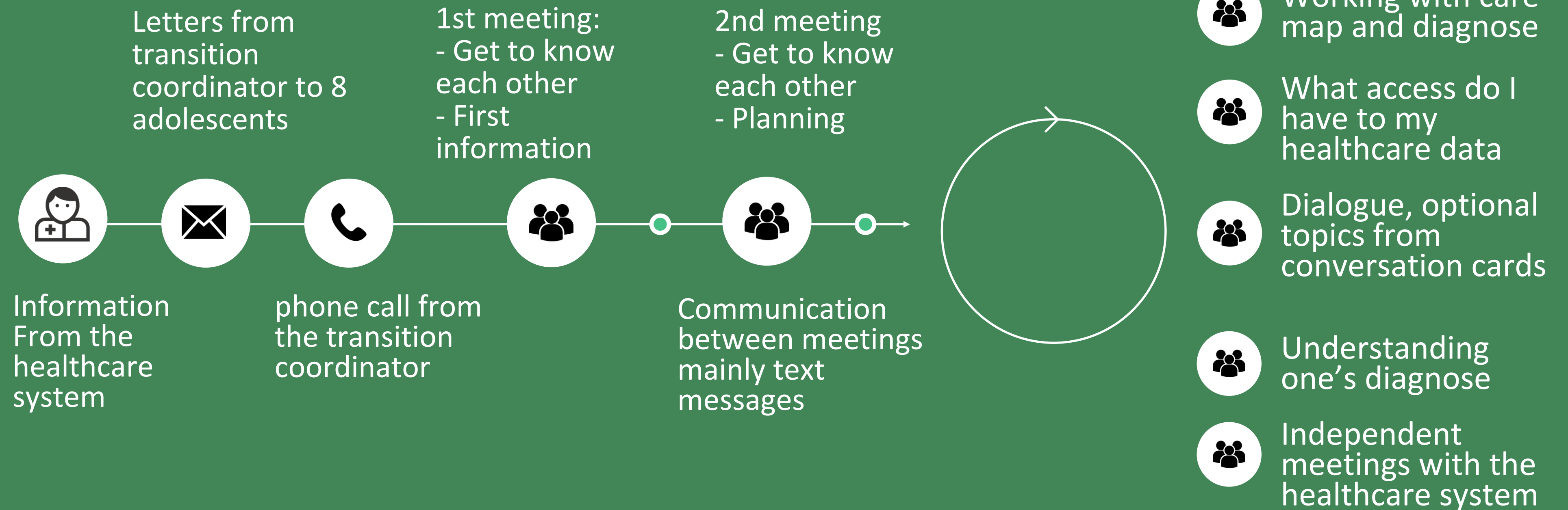


1 transition coordinator
With transition tools
and cozy room



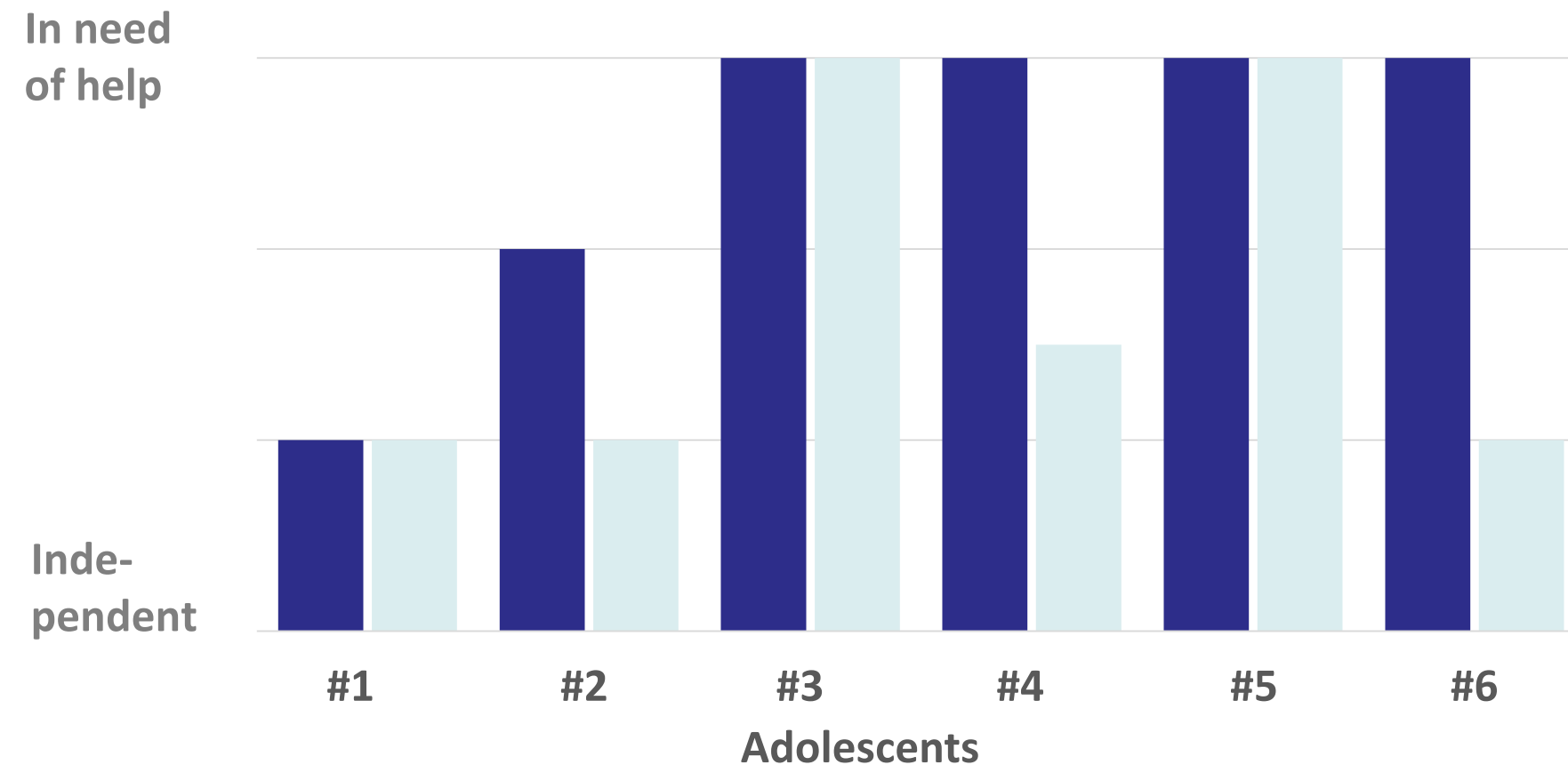
4 adolescents with a
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Alphaphilot: Meetings with the adolescents



RESULTS ADOLESCENTS

Perceived degree of independence



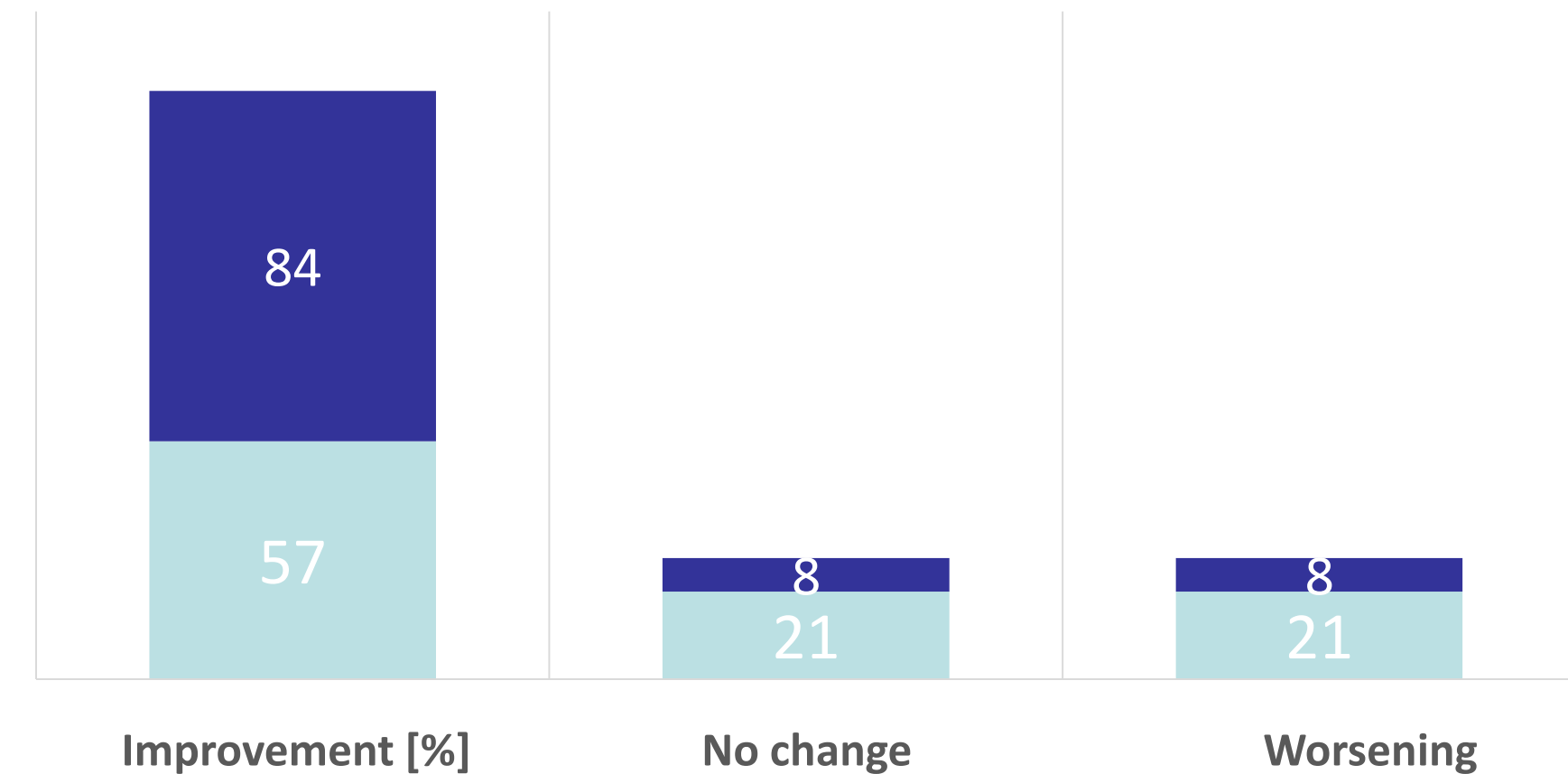
Results Adolescents:

- Increased independence
- Increased knowledge about one's diagnose and healthcare contacts
- Had important dialogues about relevant topics

Björquist, E. (2016). *Mind the gap. Transition to adulthood* <http://lup.lub.lu.se/record/8871323>
 Gorter et al. (2011). Youth in transition. doi:10.1111/j.1365-2214.2011.01336.x

RESULTS PARENTS

Worry over missing out care Perceived security



Results Parents:

- Describe adolescents as more independent
- Report increased feeling of security
- Reduced concern about adolescents healthcare
- Wish to continue the transition project

Take-home message

Helping adolescents with a chronic disease in their healthcare transition has the potential to improve their future health and their independence and will relieve their parents.

- Four promising tools:
 - ✓ Transition coordinator
 - ✓ Transition room
 - ✓ Care map
 - ✓ Conversation cards
- Easy to implement for a variety of healthcare-professionals :
 - ✓ Specialist/school nurses
 - ✓ General practitioner (GP)
 - ✓ Other healthcare counselor
 - ✓ ...

Future prospects: getting digital!

Adolescents with a chronic illness

an important group with increased health-risks

Adolescent-friendly health services

Need to provide adequate information, a safe and supportive environment and adequate counselling services:

- Confidential, respectful, professional, friendly and obliging
- Showing an open attitude
- Accessible services (technical solutions)
- Appealing health facilities

/ WHO 2012 / Making health services adolescent friendly

Adolescents

Are self-centered, adventurous, willing to take risks, prefer quick rewards, focused on peers

A life-phase where good & bad habits develop; the basis for NCDs (non-communicable diseases)

This leads to increased health risks at 15-24 years

Adolescent with a chronic disease

- Worse medical and disease management
- Risk to develop secondary NCD

/ WHO 2012 / Adolescent health and development

Chronic diseases / NCDs

- Reduced life expectancy and quality
- account for an estimated 86% of the deaths and 77% of the disease burden in Europe
- Increase risk for early retirement, unemployment, receiving welfare benefits, lower income
- Have negative impact of up to 6.77% on a country's GDP

/ WHO 2010 / Tackling chronic disease in Europe

Chronic diseases in adolescents

Negative outcomes already seen in adolescents

- More problems in school and jobs
- Smaller social networks
- Less independent
- Less physical active
- Increased mental health problems
- More dependent on welfare benefits
- Higher risk for unemployment
- Worse economic

/ WHO 2007 / The Adolescent with a Chronic Condition

- Adolescents in general need specific guidance towards a healthy lifestyle
- This is much more important for adolescents with a chronic illness

Literature

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- WHO 2010: Tackling chronic disease in Europe: The WHO's project **The Global Burden of Disease** estimates incidence, prevalence, severity and duration, and mortality for more than 130 major causes. It includes data since 2000 for WHO member countries http://www.euro.who.int/_data/assets/pdf_file/0008/96632/E93736.pdf
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RARE DISEASES SWEDEN

Thank you!

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