**GROWING UP WITH 22q11DS:**
Challenges of transition in care



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wonen | vervoer | vrije tijd | sport | ouders

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On Your Own Feet

22q11 Europe

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Stefan:
my stepson (now 31 years old) growing up with Fragile X syndrome

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## What is transition in care?

- the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems
- it is a multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused healthcare system
- the optimal goal of transition is to provide healthcare that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound, and comprehensive

(Blum et al. Journal Adolescent Health 1993)

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## Transition ≠ transfer

**Transition and transfer**
Typically, the term transition describes the period of preparation prior to and after the event of transfer, which describes the actual shift from pediatric to adult healthcare including transfer of health information. Most guide-

transition refers to the **process** of the young person becoming a partner in health care; the transfer is an **event**, part of the process

(Kennedy & Sawyer, 2008)

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## Transition to adult care AND transition to adulthood

- **managing your own care**: adolescents with chronic conditions need to take over responsibility from parents
- ▸ *active involvement of young people as partners in care*
- **managing your own life**: social participation & empowerment
- ▸ *active involvement of young people in society*

## Why transition?

- ❑ it is part of normal development …
- ❑ it indicates positive growth, achievement …
- ❑ it is what young people want …
- ❑ it recognises their potential, enhances their independence
- ❑ paediatric services not prepared for adult challenges / issues



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*I am getting too old for the children's hospital, I am a grown-up now*

*it was just like falling in a deep hole, everything I knew and trusted was gone all of a sudden*

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## Transition: is it different in 22q11DS?

transition is challenging for many young people and their parents with long-term conditions, but even more so

- ❑ for those with intellectual/ learning disabilities
- ❑ for those with rare disorders
- ❑ for those with comorbidities and complex care needs
- ❑ for those experiencing anxiety or other psychiatric disorders

While basic principles are the same, transition may be more complex in 22q11DS

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## Basic principles

The basics of transition are simple:

1. Prepare young people and their families well in advance
2. Prepare and nurture adult services to receive them
3. Listen to young people's views

Viner, Archives Diseases of Childhood 2008

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## Listen to young people's voices

- ❑ Had to get used to new hospitals
- ❑ Loads of appointments
- ❑ I don't like different hospitals for my appointments
- ❑ I don't like to go in on my own
- ❑ My mum has to go with me
- ❑ Little knowledge of 22q
- ❑ I don't remember what the doctor said
- ❑ Each individual with 22q is different
- ❑ Planning helps to develop trust in the change

YEEP 22q11

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## Young people's and parents experiences (across various conditions)

- ❑ large differences between paediatric and adult care
- ❑ lack of preparation; transfer is too abrupt
- ❑ lack of involvement in decision making of young people
- ❑ lack of access to and acceptance in adult services
- ❑ lack of integrated care
- ❑ parental involvement often discouraged in adult care

- ❑ young people have no general preference for paediatric services; but have clear views about 'good care' and 'good care providers'
- ❑ parents more concerned than adolescents

van Staa et al. Child Health Care & Development 2011

## Young peoples' experiences of transferring to adult care

can be summarized in four themes

1. facing changes in significant relationships
2. moving from a familiar to an unknown ward culture
3. being prepared for transfer
4. achieving responsibility

Fegran et al. 2013 International Journal Nursing Studies

## New NICE guideline (2016)

consensus on overarching principles

❑ involve young people & carers in service design, delivery & evaluation
❑ transition support must be developmentally appropriate
❑ transition support must be strengths-based
❑ person-centred approach (holistic)
❑ ensure smooth and gradual transition
❑ collaboration between adult care / paediatric care

NICE Guideline on transition 2016

## New NICE guideline (2016)

consensus on transition planning

❑ early start (13 years at latest)
❑ make a transition plan
❑ appoint a named worker
❑ involve young people
❑ involve parents / carers
❑ meeting adult care in advance (transition clinic)
❑ provide information about services and support available in adult care
❑ involve primary care (GP)
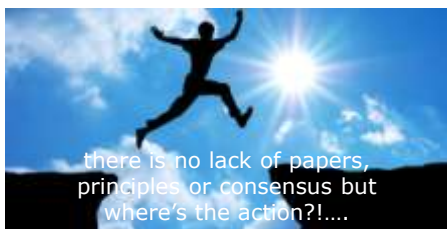
NICE Guideline on transition 2016

## How to achieve safe and effective transition to adult care

1. cultural shift in staff attitudes and training
2. put effective transition programmes in place
3. train young people to become active partners in care

Viner, Archives Diseases of Childhood 2008

## Bridging the gap

there is no lack of papers, principles or consensus but where's the action?!….



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## Transitional care interventions

| Interventions to improve the organisation of transitional care |
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| Multidisciplinary team meeting about patients to be transferred (*team communication*) |
| Joint clinics: Transition clinic (*meeting adult team before transfer*) |
| Transition protocol / structured programme |
| Transition coordinator / Transition coach (*key worker*) |
| Joint treatment protocol and policies between paediatric and adult care |
| **Interventions to enhance self-management / empowerment** |
| Transition Plans / Ready Steady Go or Skills for growing up |
| *Welcoming parental involvement* while encouraging youth empowerment |
| Seeing adolescents independently during part of the consultation |
| Health passport |
| Leaflet / website / information meeting about transition |
| Peer support: meeting fellow patients, camps, buddy system |

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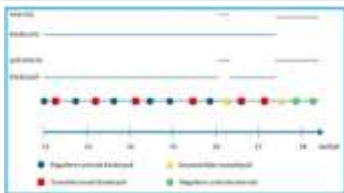
## A) Improving service delivery

Transition clinic
- Close collaboration between paediatric and adult care, through
  - ❑ Joint appointments / joint clinics
  - ❑ Pairing between professionals of PC - AC
  - ❑ Multidisciplinary Transition Meetings between AC and PC teams
- Aims:
  - ❑ Smoothen the transfer for young person & parents
  - ❑ Prevent disengagement from services
  - ❑ Align treatment protocols and procedures

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## Transition clinic (joint care)



- ❑ Many different models co-exist in practice; little evidence for (cost)effectiveness
- ❑ Organisational challenges
- ❑ Meeting adult team before transfer is beneficial

## B) Promoting self-management

Work gradually on promoting more independence and autonomy in daily life
- Close collaboration between young person and parent
  - ❑ Teaching life skills
  - ❑ Early start
- Aims:
  - ❑ Gradual shift of responsibilities from parent to young person
  - ❑ Enhance self-efficacy / empowerment
  - ❑ Better social outcomes

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## Skills for Growing Up (ID-version)



www.opeigenbenen.nu/onderzoek/projecten/epilepsie-groei-wijzer/

## Skills for Growing Up (ID-version)

- A self-management action plan aimed at enhancing self-efficacy & autonomy
- Focuses on young person; parents are involved
- Promotes 'normal' development: serves as a road map to (more) independence for young people
- Encourages holistic conversations about independent life skills in nine life areas
- It is **not** a validated questionnaire or measurement tool
- Two age-specific versions (ID-version)
  7-13 years
  14-21 years

Sattoe et al., Journal of Renal Care, 2014; Hilberink et al. in process

## Skills for Growing Up (ID-version)

*The questions are not really difficult*

*I learnt quite some things from that list*

## **Healthcare professionals**, transition is about good quality care

Young people place high value on clinics in which:
- Information was passed on to the right person
- Parental involvement was welcomed
- Staff gave them choices and allowed them to make decisions about their care
- They saw the same staff at each clinic
- They provided extra support to help young people prepare for everyday life with their condition in future

Colver, Rapley et al. The Transition Research Programme 2017

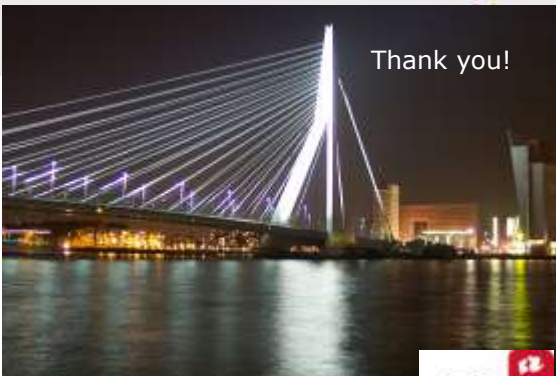## **Young people:** transition is about speaking up for yourself!

speak up!

## **Parents**, transition is **not** about "letting go"...

LET GO

**but** about changing the way you hold onto your child!

Thank you!

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5