



# Services for youngsters with ADHD and related disorders: Status and policy

Conference: Family polices and child welfare in the Nordic countries – 5.9. 2014

# For clarification

- ***Youngsters*** Children aged 5 to 18 years
- ***Services*** Recommended best practice for diagnosis and treatment
- ***ADHD*** A few words on definition and diagnosis
- ***Related disorders*** The most common problems (symptoms or disorders) that co-occur with ADHD
- ***Policy*** and ***Status*** What is the official policy in Iceland and how we are doing re. services?

# What is ADHD?

## Attention Deficit Hyperactivity Disorder

“is a condition that robs children of their ability to focus and pay attention”

“Kids with ADHD are fidgety and easily distracted which makes it difficult to stay on task, whether it's listening to a teacher or finishing a chore”

# What is ADHD?

- ADHD is a neurologically based behavioural disorder, characterized by symptoms of inattention, hyperactivity and impulsivity
- Inattentive Symptoms: trouble keeping on task, following directions and completing homework or other tasks, unorganized, seem not to listen, often loses things, easily distracted and forgetful
- Hyperactive-Impulsive Symptoms: fidgeting, trouble remaining seated, talking excessively, always on the go, difficulty playing quietly, blurting out answers, trouble waiting patiently, and interrupting others



**“Occasionally, we may all have difficulty sitting still, paying attention or controlling impulsive behaviour”**

**“For a person with ADHD, though, these problems become so pervasive and persistent that their ability to function effectively in daily life is compromised”**

# Normal vs. disruptive levels

- Most people show symptoms of ADHD, but that does **not** mean they have ADHD
- To be diagnosed with ADHD, the symptoms must be present over time (at least six months) and be at a level that is both **disruptive and inappropriate** for the person's age and developmental level
- Only those who have psychological, social and/or emotional **impairment** should be diagnosed with ADHD

# Guidelines for diagnosis and treatment of ADHD

- The British NICE\* guidelines are widely used
  - \*National institute for Health and Care Excellence, [www.nice.org.uk](http://www.nice.org.uk)
- In Iceland clinical guidelines were first issued by the Directorate of Health in 2007, reviewed in 2012 and in 2014 a short and revised version was issued <http://www.landlaeknir.is/gaedi-og-efirlit/heilbrigdisstarfsfolk/klininskar-leidbeiningar/leidbeiningar/item14931/ADHD---vinnulag-vid-greiningu-og-medferd>
  - These are closely based on the NICE guidelines
- The diagnostic criteria of DSM-5\* are used although the ICD-10\* is used for recording and classification purposes
  - \*The Diagnostic and Statistical Manual of Mental Disorders
  - \*International Classification of Mental and Behavioural Disorders

# Guidelines for ADHD diagnosis

- Multidisciplinary team, including psychological and medical professionals specialised in ADHD
- The diagnosis consists of gathering a wide range of information about the child's history, behaviour, abilities and affect across different situations
- Assessment tools include structured interviews, tests, observation and checklists to cast light on the child's cognitive, social and emotional capabilities, strengths and weaknesses
- The symptoms must cause impairment and not be better explained by other disorders



# ADHD rarely occurs alone!

- Children with ADHD often also have problems with behaviour, peer relationship, anger management, self-esteem, communication, emotional control and anxiety
- Many get additional diagnoses (comorbidities), such as oppositional defiant disorder (ODD), conduct disorder (CD), anxiety disorders, autism spectrum disorders, tics or Tourette

# Differential diagnosis

- To determine which of several disorders that present with similar symptoms may be producing the symptoms
- A variety of methods and the involvement of experts from different professions
- Addresses the question whether the child has ADHD, another disorder, one or more

# Recommended treatment\*

- Preschool and primary school children:
  - Parent-training/education programmes that are based on **social learning model** and involve both parents
  - Behavioural and educational intervention in the classroom by trained teachers
- School aged children:
  - Same as above, **and**
  - Drug treatment is to be considered **if** other interventions have not been affective alone

\* According to NICE and the Icelandic guidelines

# Diagnosis vs. treatment?



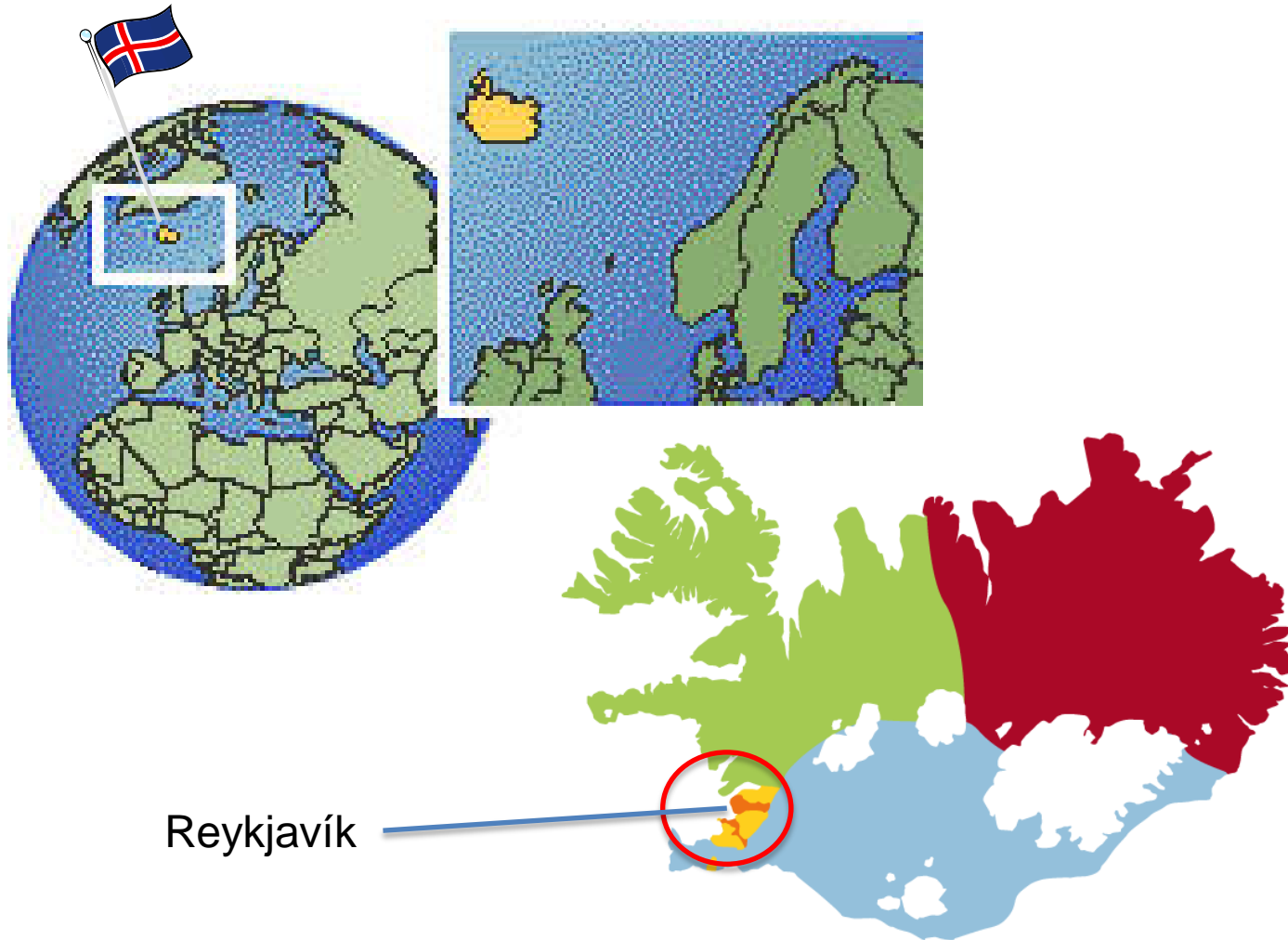
- “Too much emphasis on diagnosis, not enough on treatment”
- This is **not** a question of one **or** the other!
- The purpose of diagnosis is intervention
  - Improve present skills and abilities
  - Reduce present difficulties, behaviour problems, conflict, suffering etc.
  - Prevent escalation of existing problems
  - Improve future quality of life

# ADHD and drugs

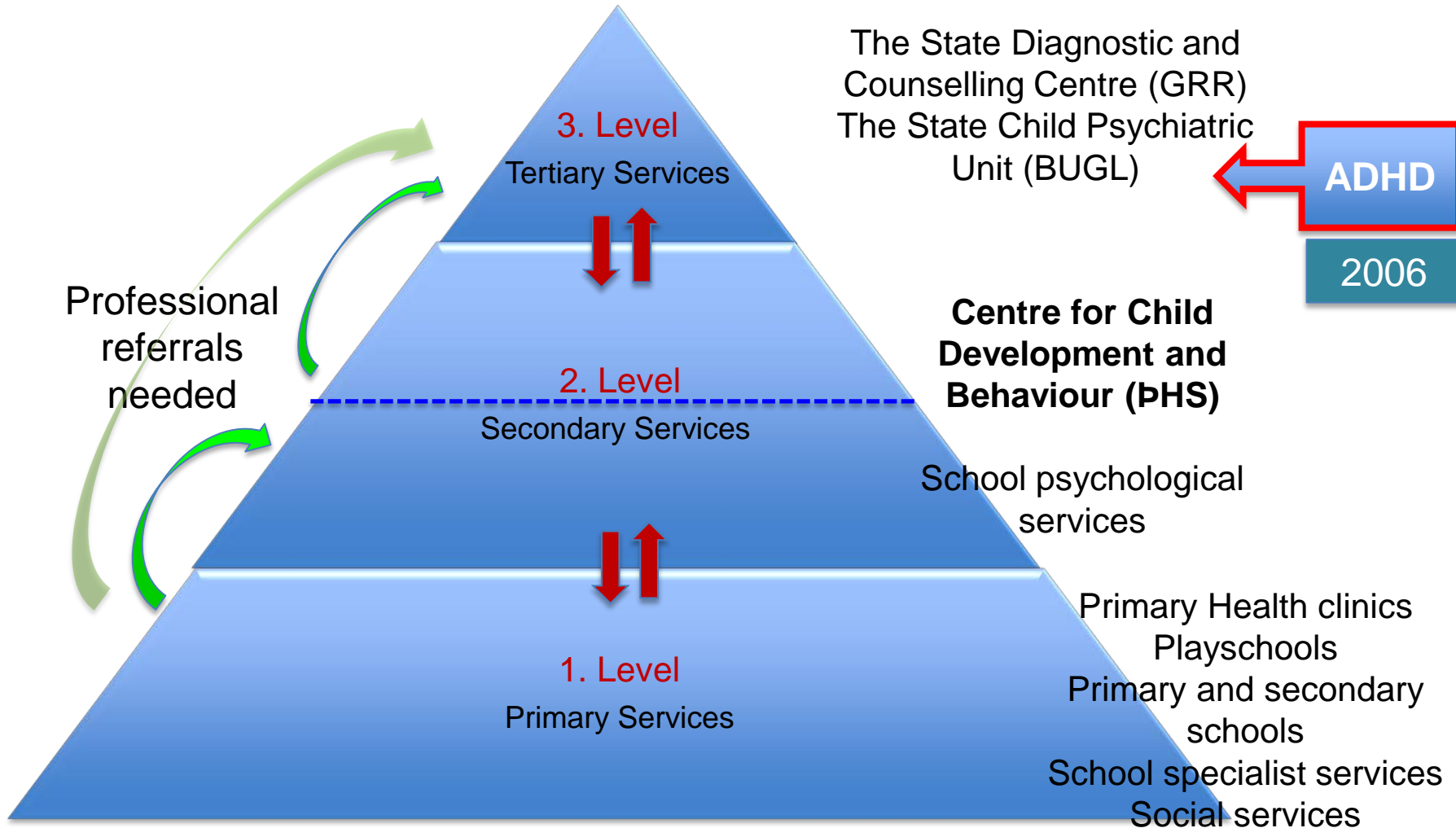
Children with ADHD are at a significantly **greater risk** for substance abuse problems than other children

Effective medical treatment for ADHD **decreases the likelihood** of substance abuse problems

# ADHD services in ICELAND



# Services for children in Iceland



# Assessment pathways

- Children with attention, hyperactivity, behaviour or interpersonal problems, anxiety, low mood or autistic symptoms
- Worries/problems noted by teachers and/or parents
- Referral to school specialist services for “primary assessment”
  - Cognitive testing, observations, screening of behavioural and emotional problems (ADHD rating Scale, CBCL, SDQ, ASSQ)
- Referral to secondary/tertiary services for “further assessment”
  - Differential in-depth assessment by a multidisciplinary team according to clinical guidelines
  - The most severe/complex/acute psychiatric problems → BUGL
  - Children with IQ under 70, some also with ASD symptoms → GRR
- The moderate/severe ADHD, behaviour and mood problems and autistic spectrum symptoms without mental retardation → **PHS**



# Services for children at PHS

## Centre for child development and behaviour



- A specialized service centre
- Part of the capital area primary health care
- Serves greater Reykjavik **and** other areas as needed
- Assessment/diagnosis of developmental and behavioural problems/disorders
- Parent training/education programmes
- Group and individual treatment for children

# Model for the ADHD service

- Early identification and screening of problems/symptoms
  - Primary intervention
- Primary assessment of symptoms and need for further assessment
  - Intervention based on first indications
- Further more thorough and specialized assessment for differential diagnosis
  - Specialized intervention/treatment/follow-up

# ADHD\* referrals at PHS

- Year 2013: New referrals **265\***
  - Rejected/referred elsewhere **42**
  - Multidisciplinary assessment **153**
  - Were added to the waitlist **70**
- 2014 – first 8 months: New referrals **229\***
  - Rejected/referred elsewhere **17**
  - Multidisciplinary assessment **150**
  - **Now waiting for ADHD assessment 228**
  - **Waiting time up to 12 months**

\*ADHD and related disorders, mainly 5 years and older. Younger children with other developmental or behavioural problems not included

# What needs to be done

- The UN Committee on the Rights of the Child gave a clear message in Oct. 2011
- **Diagnostic accuracy** should be improved
- **Waitlists** for diagnostic and treatment services **were too long** for children with ADHD and similar disorders
- Children's **mental health services should be reinforced** in order to increase their capacity

# What has happened since then?

- Overall there is good adherence to clinical guidelines re. diagnostic practice, **BUT**
- There has been a steady increase in the number of children referred for specialized service
- More and more children wait far too long
- The capacity of services has hardly increased per se and is further away from meeting the need now than in 2011

# Developments in public service

- The availability of skills training programmes for parents has increased
- The availability of skills training for children has increased, but not enough
- Execution and content of treatment mostly follows clinical guidelines
- The state of knowledge among professionals is mostly good
- Increased awareness and knowledge in the school system – better service in schools

# ADHD: Policy in Iceland?

- No clear service policy for children's ADHD
- Wait for service is mostly too long
- Many children miss out on vital treatment and thus suffer and face unnecessary risks
- Although access to private psychology service for children has increased, this is still not subsidized by the national insurance system

# So, what needs to be done?

- **Policy** making at ministerial level with a clear aim built on evidence based knowledge
- Comprehensive **strategy** for the service of children with ADHD
  - How many children need services each year?
  - What kind of services do they need?
  - Where should the service be on offer?
  - What institutions are responsible?
- A **definite plan** of implementation



**And finally ...**

**Action is needed now!**

**The policy and implementation must take serious notice of the UN recommendations as well as clinical guidelines for best practice!**

**Otherwise we will be facing a much bigger problem ...**