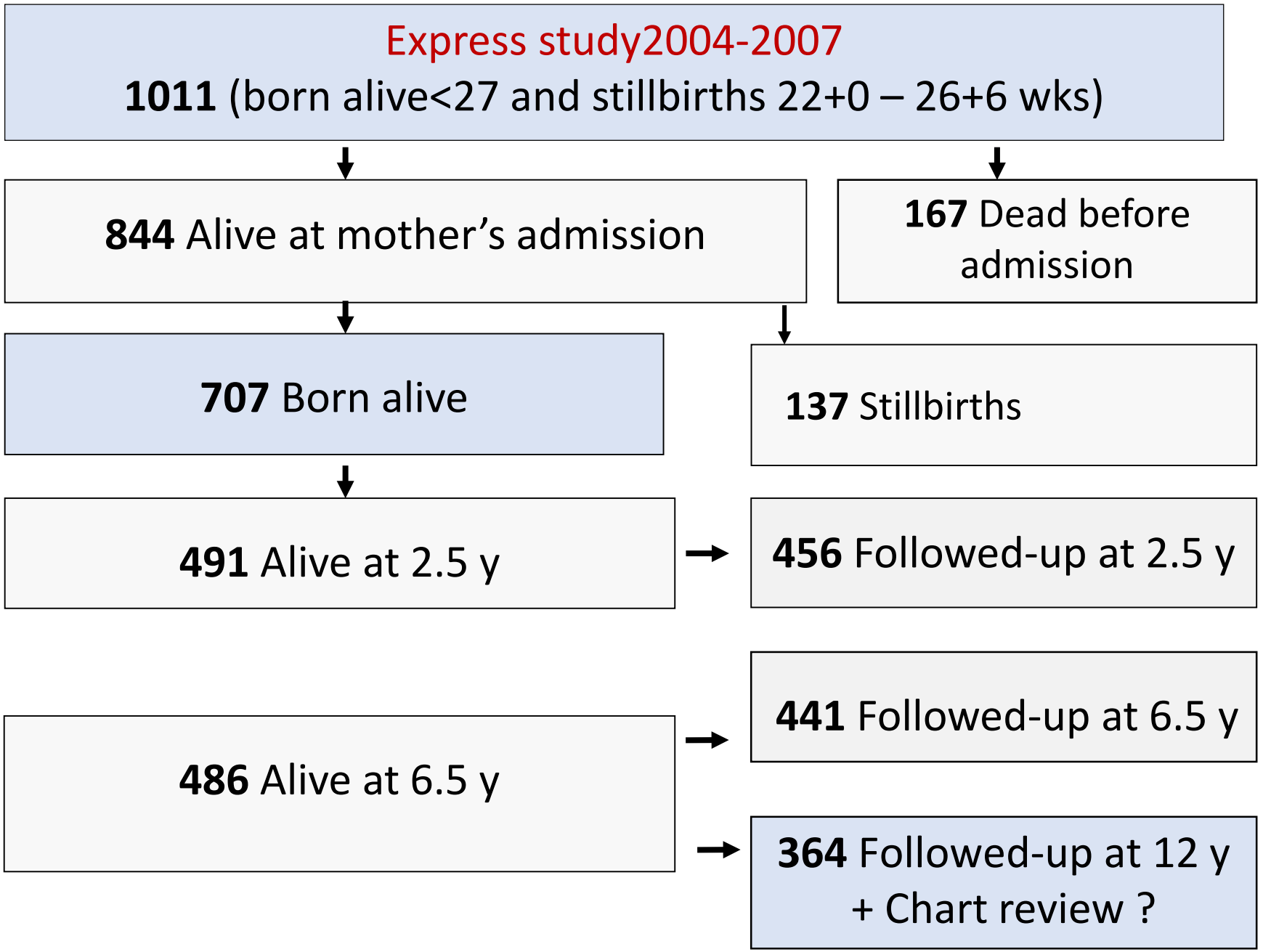
Motor impairments and comorbidities at 6.5 years in apparently healthy children born extremely preterm (NDD-free EPT children)

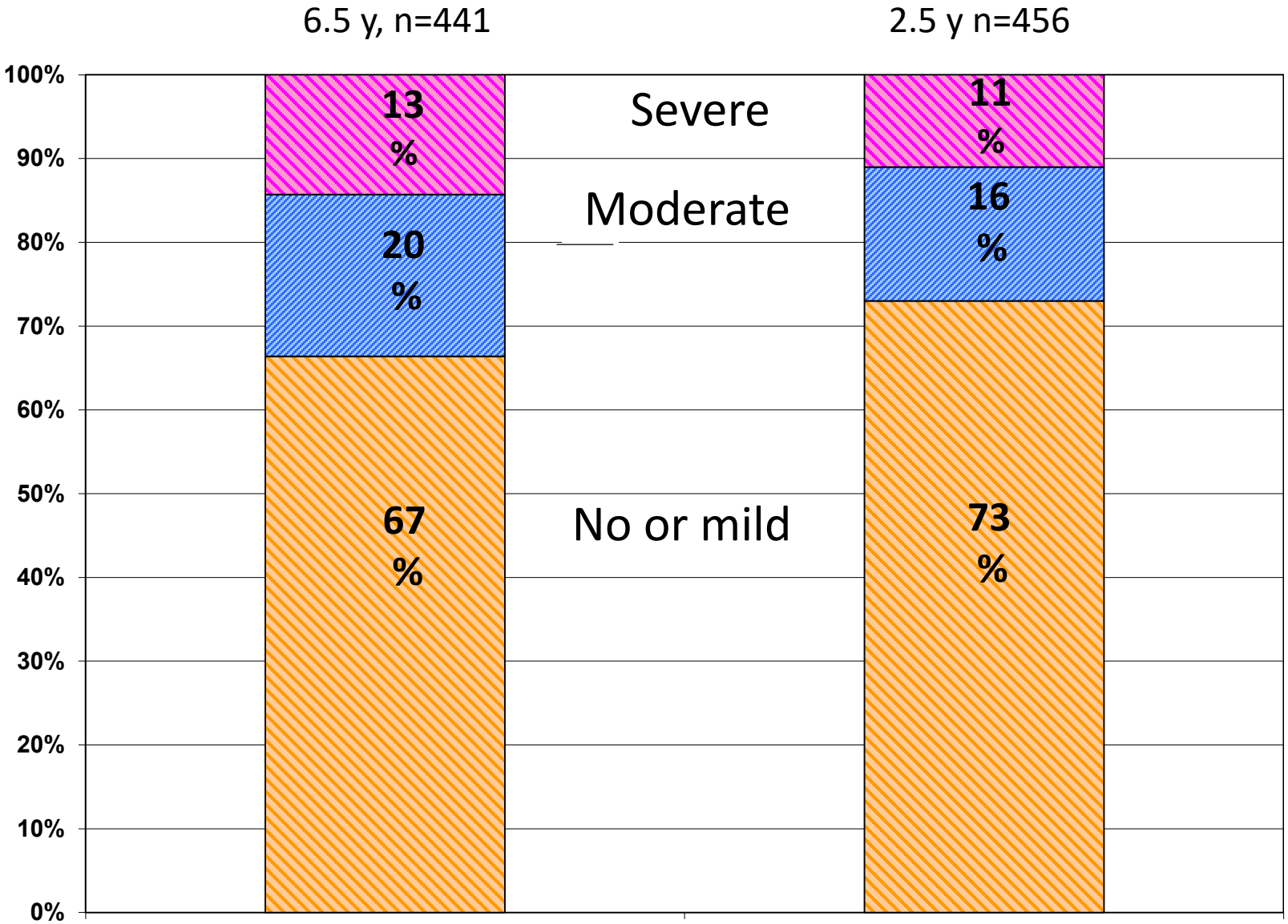
The EXPRESS study

Fredrik Serenius
Uppsala and Umeå Universities


Express study2004-2007
1011 (born alive<27 and stillbirths 22+0 – 26+6 wks)
844 Alive at mother's admission
167 Dead before admission
707 Born alive
137 Stillbirths
491 Alive at 2.5 y
456 Followed-up at 2.5 y
486 Alive at 6.5 y
441 Followed-up at 6.5 y
364 Followed-up at 12 y + Chart review ?

Disabilities at 6.5 and 2.5 yrs

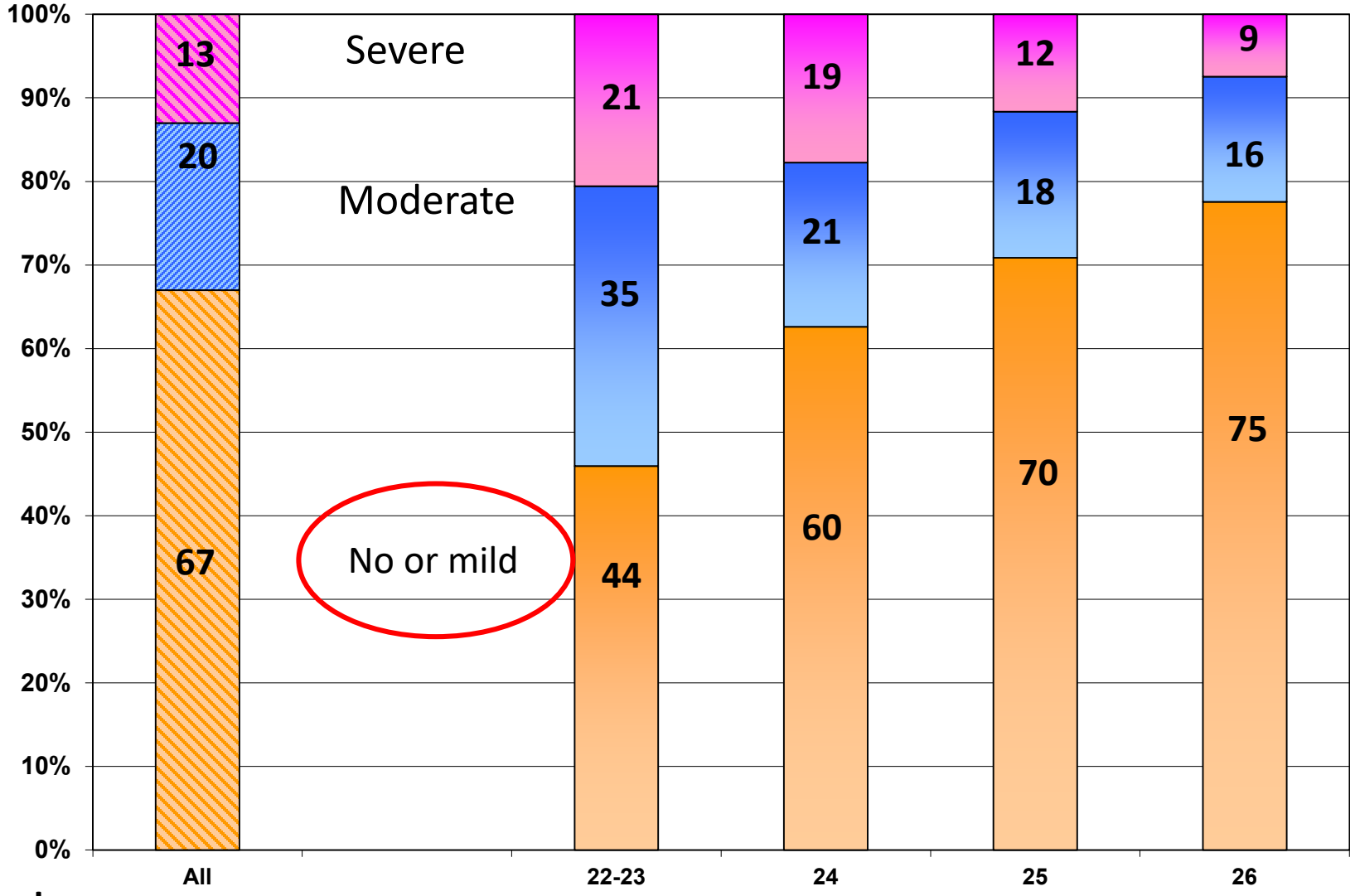
(Either CP, blind, deaf or intellectual disability)



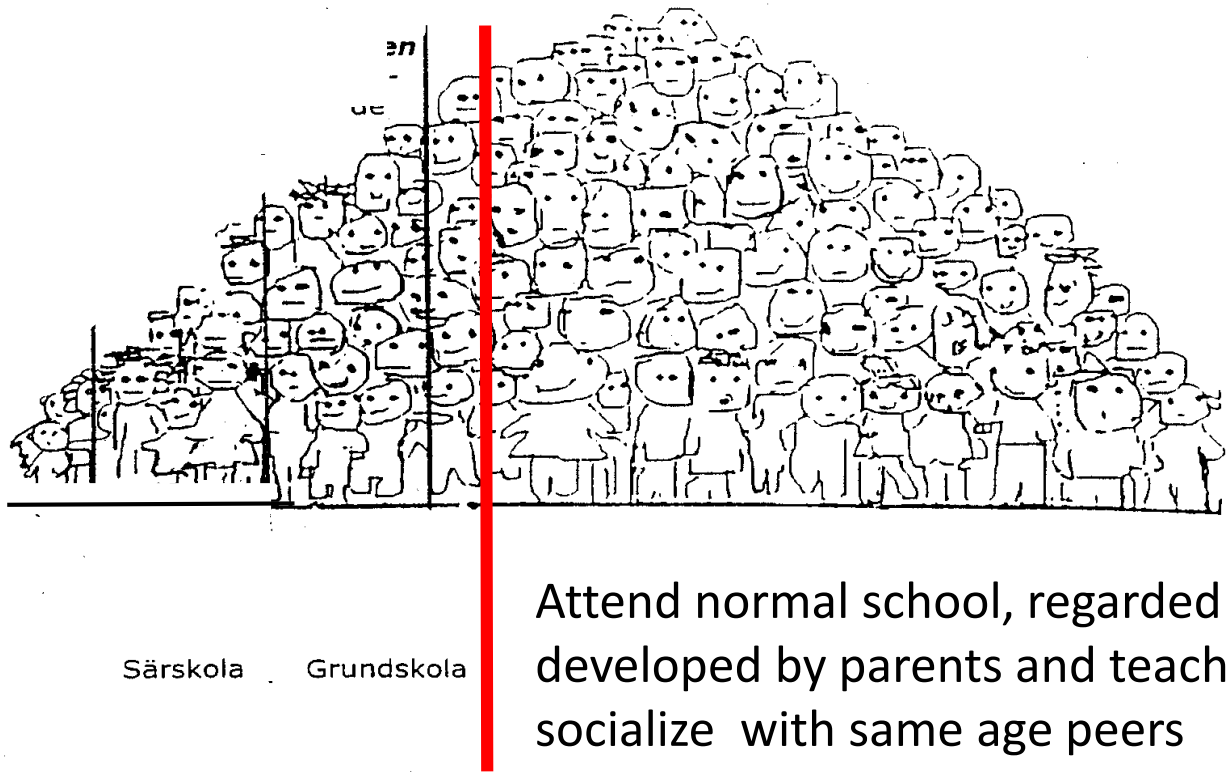
Kognition: WISC-IV. Intellectual disability: IQ < -2 SD relative to controlgroup.

Disabilities at 6.5 years

(Disability: Either CP, blind, deaf or intellectual disability) n= 441



Serenius F, et al., JAMA Pediatrics, 2016;170:954-63



Attend normal school, regarded as normally developed by parents and teachers and socialize with same age peers

Baserad på teckning
av psykolog
Ingrid Adolfsson,
Huddinge

Clumsiness

Pioneering studies on motor difficulties started in the 1940s and and often described in pejorative terms:

”….he is awkward in movements, poor at games, hopeless in dancing and gymnastics, a bad writer and defective in concentration. He is inattentive, cannot sit still, leaves his shoelaces untied, does buttons wrongly, bumps into furniture, breaks glasseware, slips off his chair, kicks his legs aginst the desk, and perhaps, reads badly.”

(BMJ 1962, quoting Annell 1940)

…”bad manners”

What is Developmenta coordination disorder (DCD)?

Characterized by marked impairment in motor coordination

Diagnostic criteria (according to DSM5 and ~ICD-10, 82.9)

1. Lower-than-expected motor skills given chronological age;
2. Skill deficits that significantly and persistently interfere with daily living;
3. Symptoms that occur early in the developmental period;
4. Motor deficits that are not better explained by intellectual disability, visual impairment or another neurological condition affecting meovement (e.g. CP)

DCD prevalence: About 3-5 % in the general population; Higher among males, much higher in preterm populations.

Functional presentation

Fine or gross motor impairment or both.

Difficulties commonly include: drawing/writing, dressing (buttons, zips, laces), eating with utensils, pouring a drink, opening packages, brushing hair/teeth, indoor and outdoor play, games/sport, riding a tri- or bicycle, driving a car, dancing etc.

Tasks performed less accurately, takes longer to accomplish and with more fatigue.

More tired at the end of the day.

Associated with ADHD and other developmental and behavioral problems.

Do not outgrow; lifelong condition.

”Trajectory of trouble” among children with DCD

Missiuna et al. 2007

Secondary problems related to DCD

Risk for bullying and harassment,

Schoolproblems

Poor participation in social activities, social exclusion

Low selfesteem, depression, anxiety

→ The condition is lifelong

→ Cardiovascular disese.

→ Overweight or obesity.

Low quality of life

Sarahs, 9 år, känslor om fysisk aktivitet

"Well for the skipping rope it's, it's I might trip on it and fall and hurt myself. Monkey bars I lose my grip, fall. And with soccer I'm afraid I might kick it but instead of kicking it put my foot on the ball and then slip when the ball goes. And this, I'm afraid I ~~might fall and hurt~~ myself. So ~~I~~ mostly afraid."

Zwicker et al 2017

Hur fysisk aktivitet påverkar Bill, 12 år.

"I always think I'm a loser and um, you know feel kind of sad for quite a long time but I'll get over it. It's really sad and you don't ~~think you~~ can do it. And you stop trying."

Zwicker et al 2017

EXPRESS
Extremely Preterm Infants in Sweden Study

4 research questions:

1. What is the prevalence of DCD among EPT children in the EXPRESS cohort compared to controls?
2. Do NDD-free EPT children with DCD have more behavioral and developmental problems in the clinical range than controls?
3. Do NDD-free EPT children *with* DCD have more behavioral and developmental problems in the clinical range than EPT children *without* DCD
4. Did parents and the medical profession recognize theese problems

Methods:

Tests

- Motor skills: **Movement ABC**
- Cognition: **Wechsler Intelligence Scale for Children**

Screening tests

- Emotional symptoms, Conduct, Hyperactivity/ inattention, Peer relationships: Strengths and Difficulties questionnaire, **SDQ**
- Inattention: **ADD Brown**
- Developmental problems in daily life: Social, perceptual problems: **Five to Fifteen** questionnaire.

Comparison with control group born at term.
Test scores > 90 percentile of the control group distribution are scores in the **clinical range**

Movement Assessment Battery for Children – Second Edition (MABC-2)

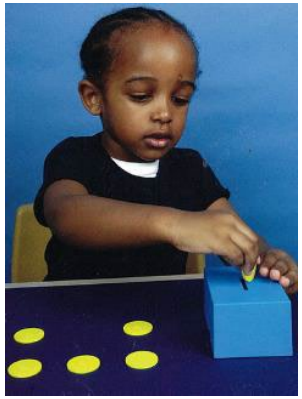
- Age band 1 (3-6 years)
  - **Manual dexterity**

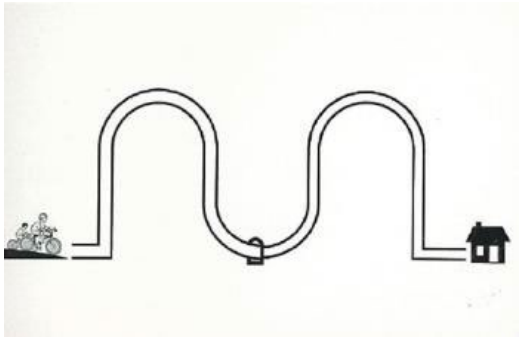
    (posting coins, threading beads, drawing trail)
  - **Aiming and catching**

    (catching beanbag, throwing beanbag onto mat)
  - **Balance**

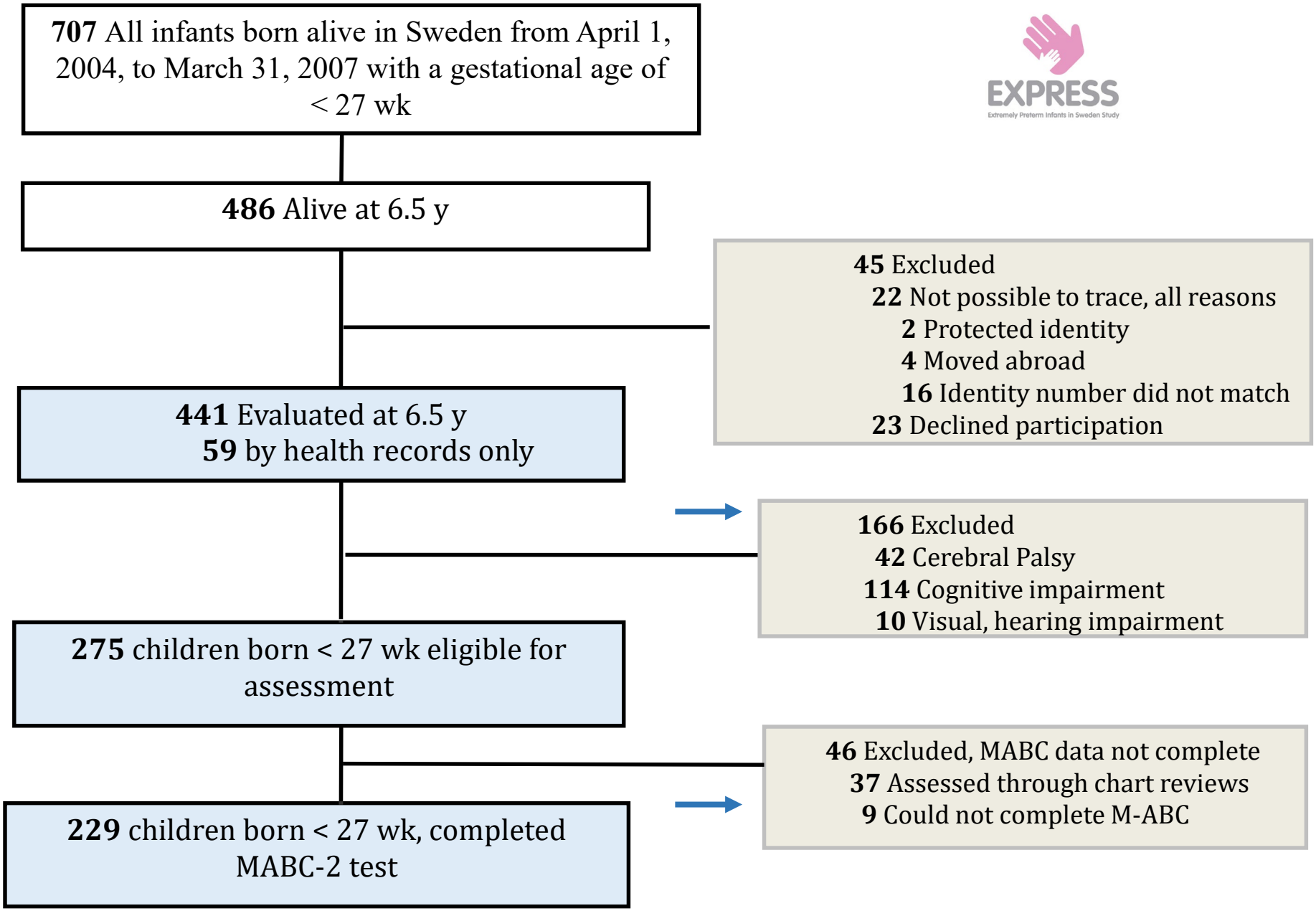
    (one-leg balance, walking heels raised, jumping on mats)

Children performing at or below the 5th percentile of our our control group considered to have DCD.

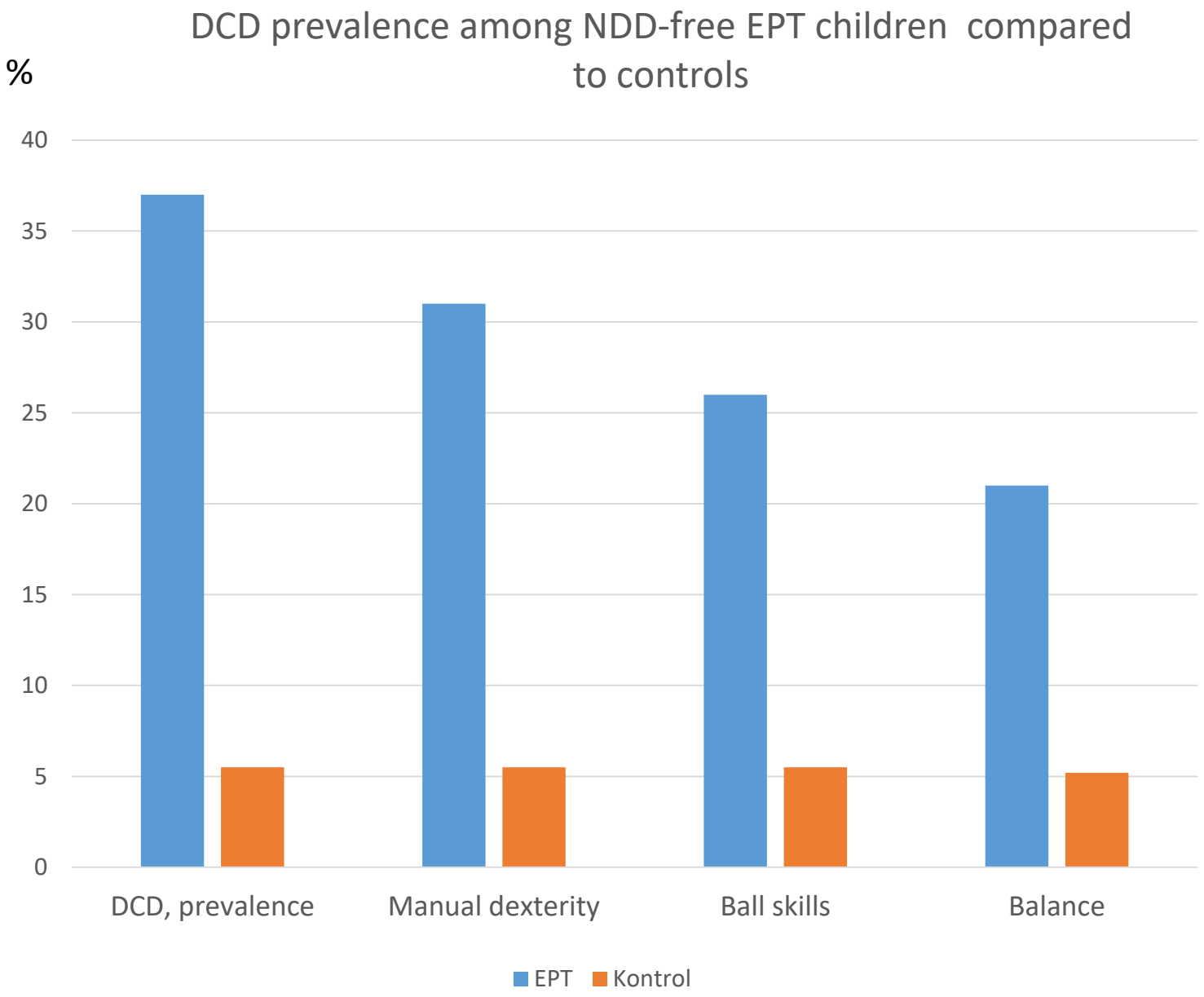




Adapted from Pearson manual


707 All infants born alive in Sweden from April 1, 2004, to March 31, 2007 with a gestational age of < 27 wk
EXPRESS
Extremely Preterm Infants in Sweden Study
486 Alive at 6.5 y
45 Excluded
22 Not possible to trace, all reasons
2 Protected identity
4 Moved abroad
16 Identity number did not match
23 Declined participation
441 Evaluated at 6.5 y
59 by health records only
166 Excluded
42 Cerebral Palsy
114 Cognitive impairment
10 Visual, hearing impairment
275 children born < 27 wk eligible for assessment
46 Excluded, MABC data not complete
37 Assessed through chart reviews
9 Could not complete M-ABC
229 children born < 27 wk, completed MABC-2 test

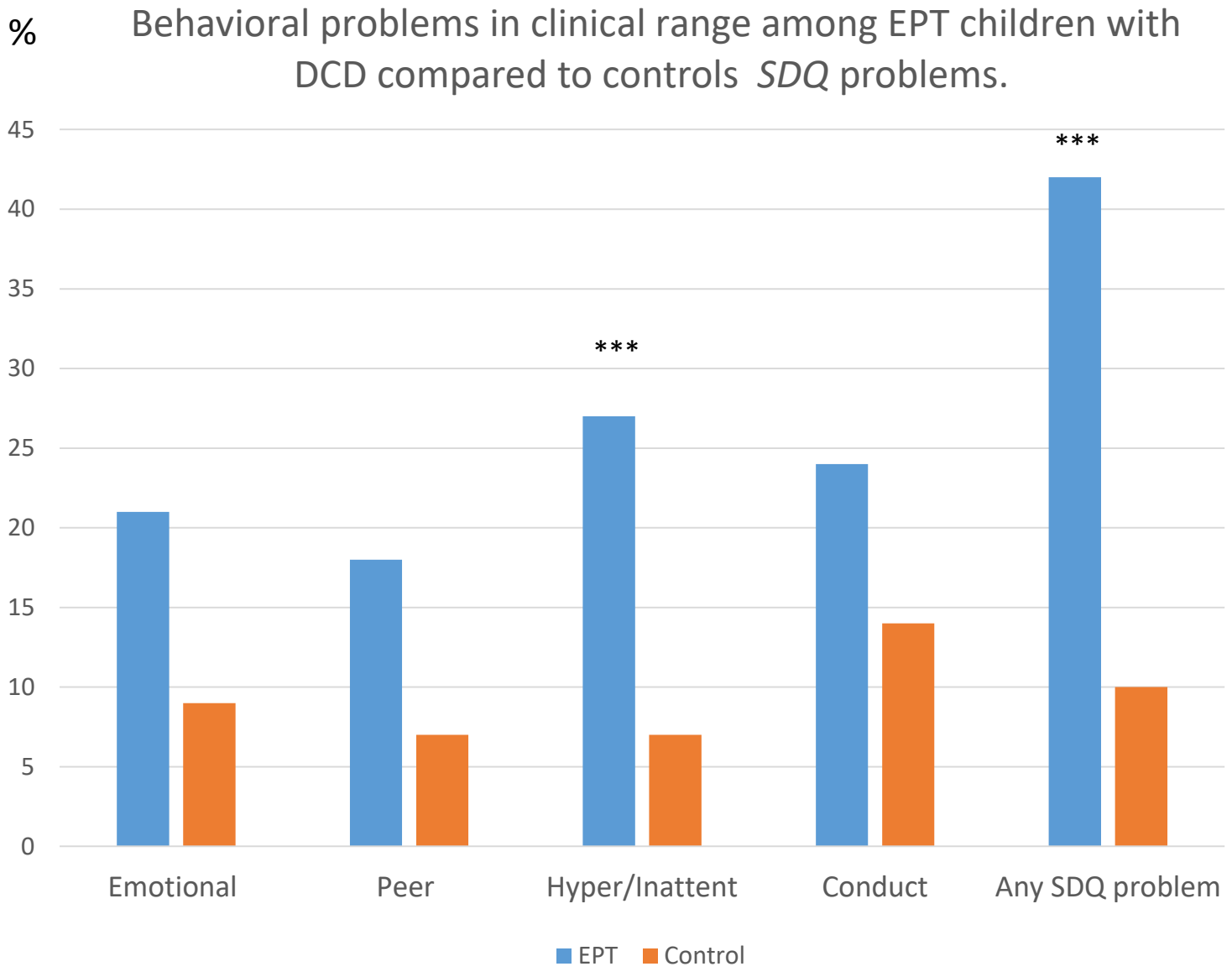
Answer to the first reserach question



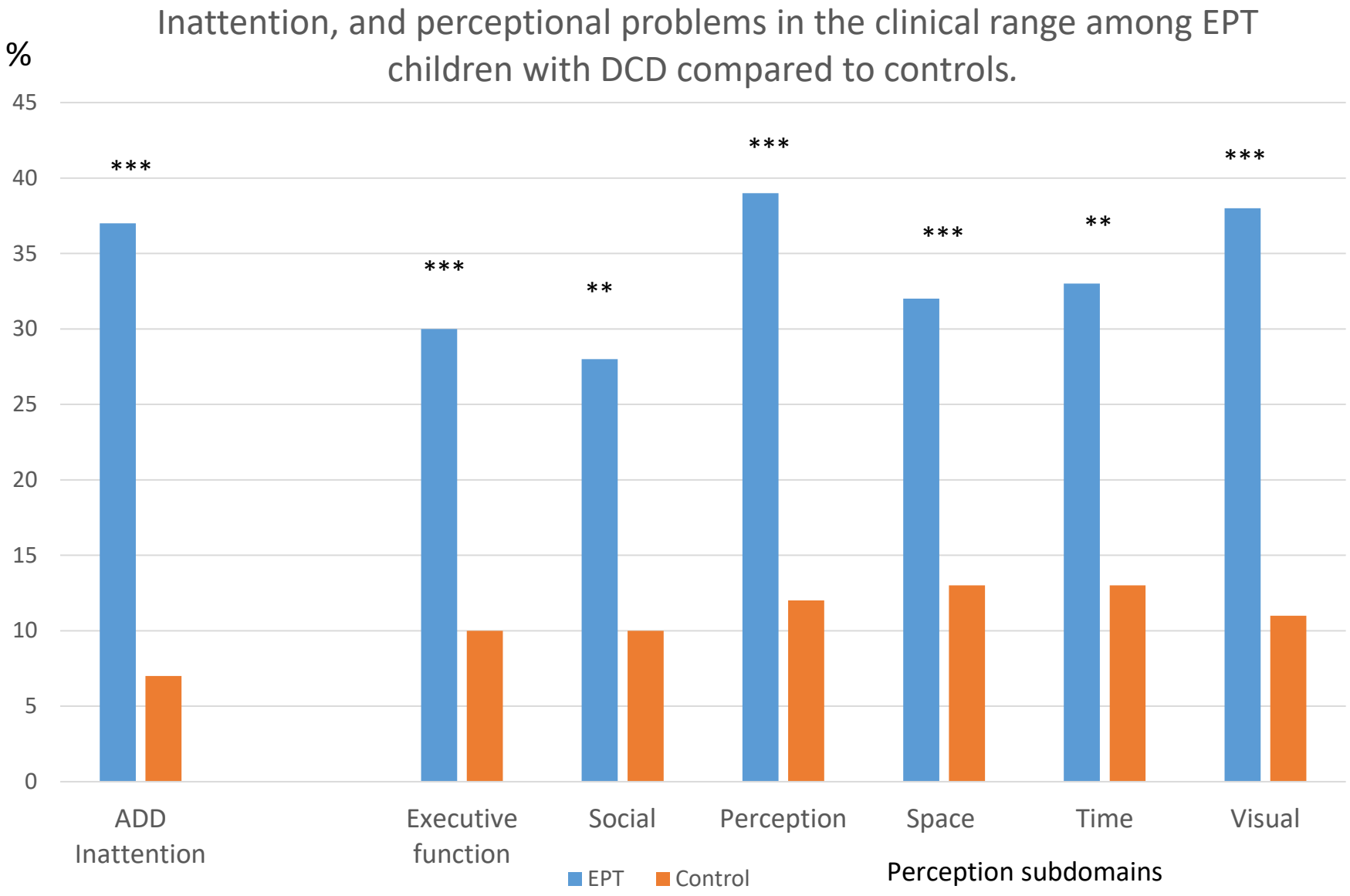
Characteristics of EPT children with and without DCD

	DCD n = 85 %	No DCD n = 144 %	Control n = 375 %
Non-Nordic mother	19	12	5
Male gender	58	46	55
Gestational age, median wk	25.4	25.9	
Small for gestational age	21	15	
Mother's education >13 år	46	55	62
Severe BPD	28	15	
IVH> grade 3	7	3	
PVL	5	1	
ROP > stage 3	40	20	
Postnatal steroids	32	10	
Mechanical ventilation, median, d	12	5	
IQ, scores at 6,5 years	88.4 (8.3)	93.3 (10.1)	100.3 (11.7)

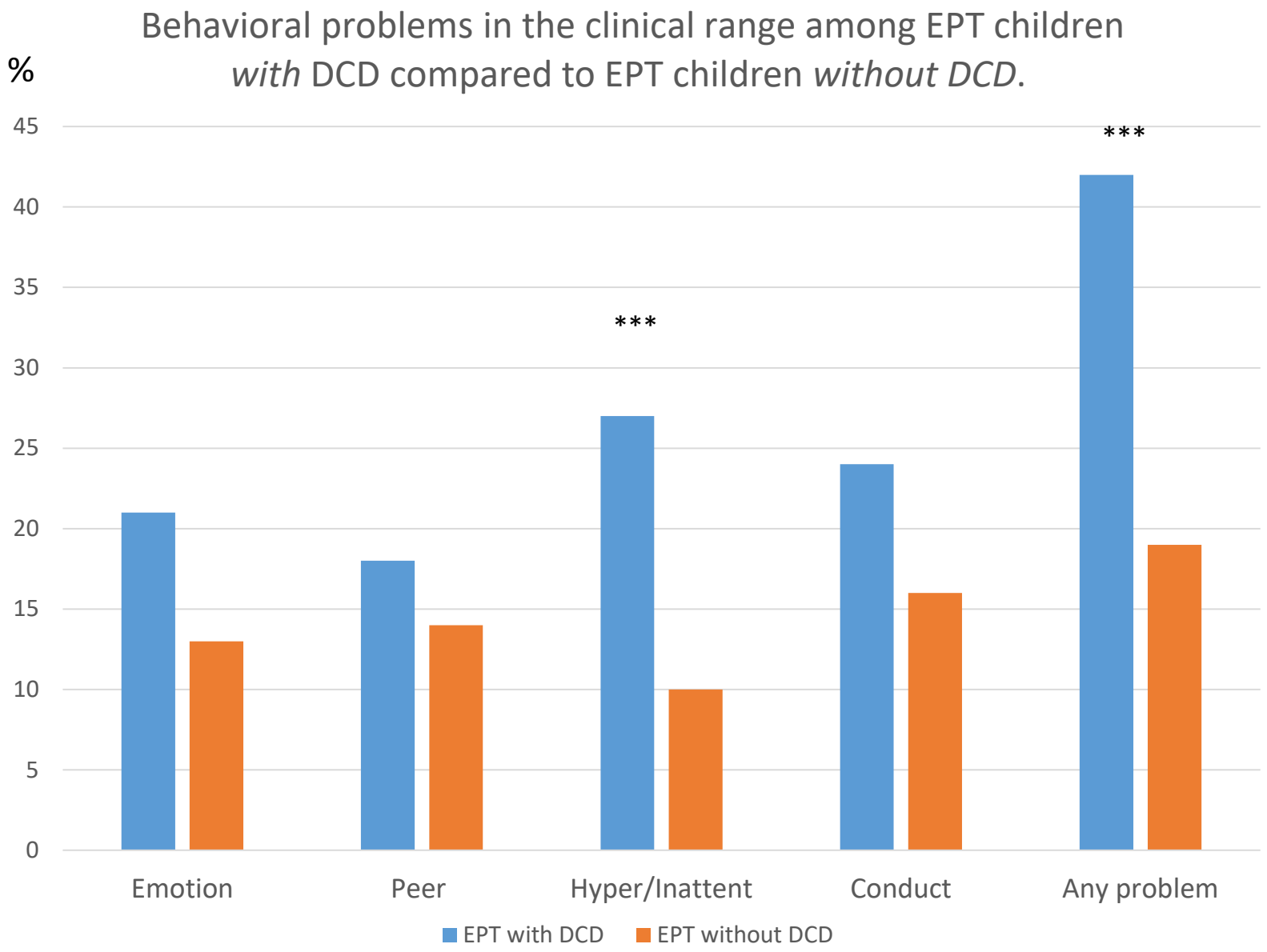
Answer to second research question (a)



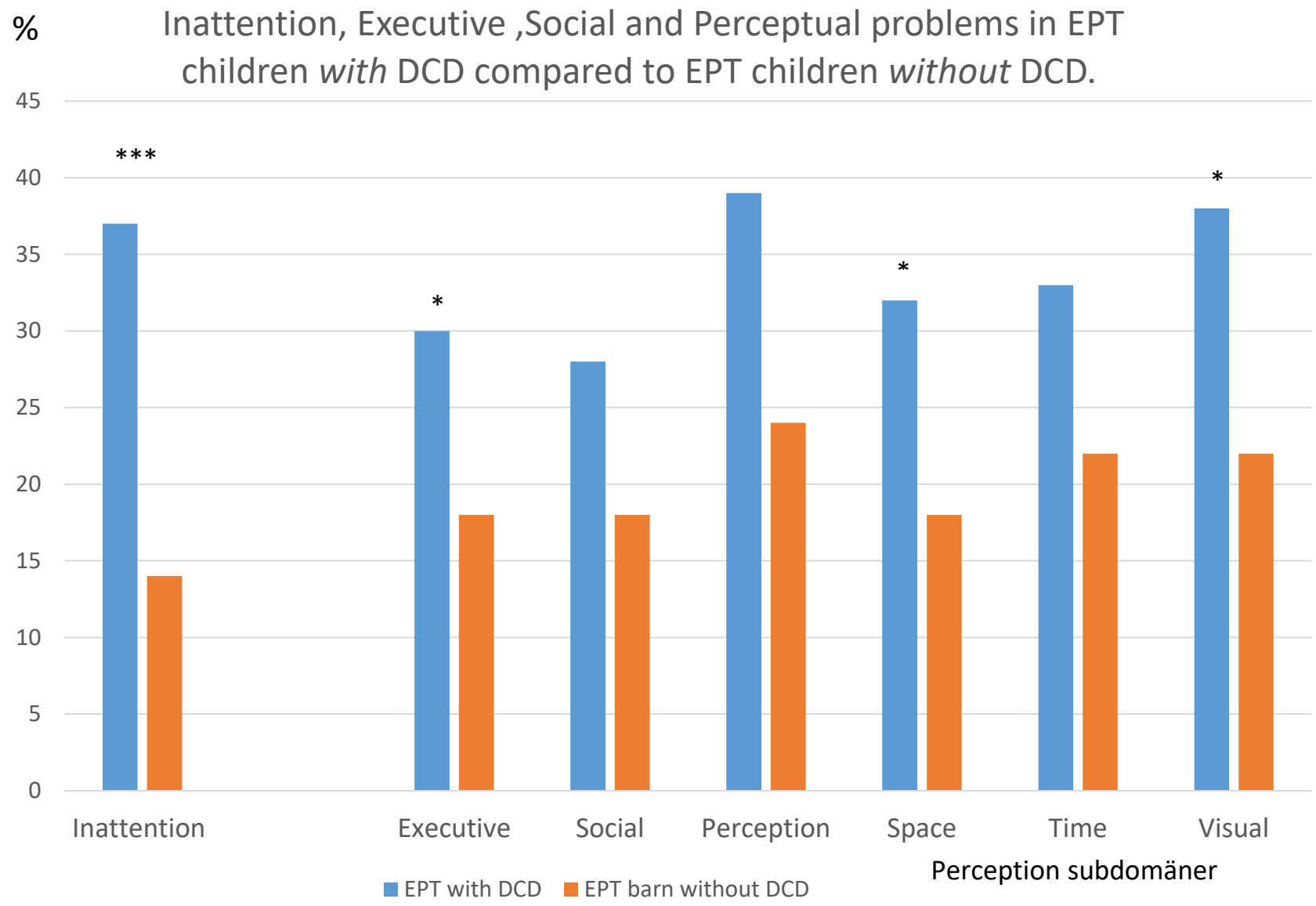
Answer to second research question (b)

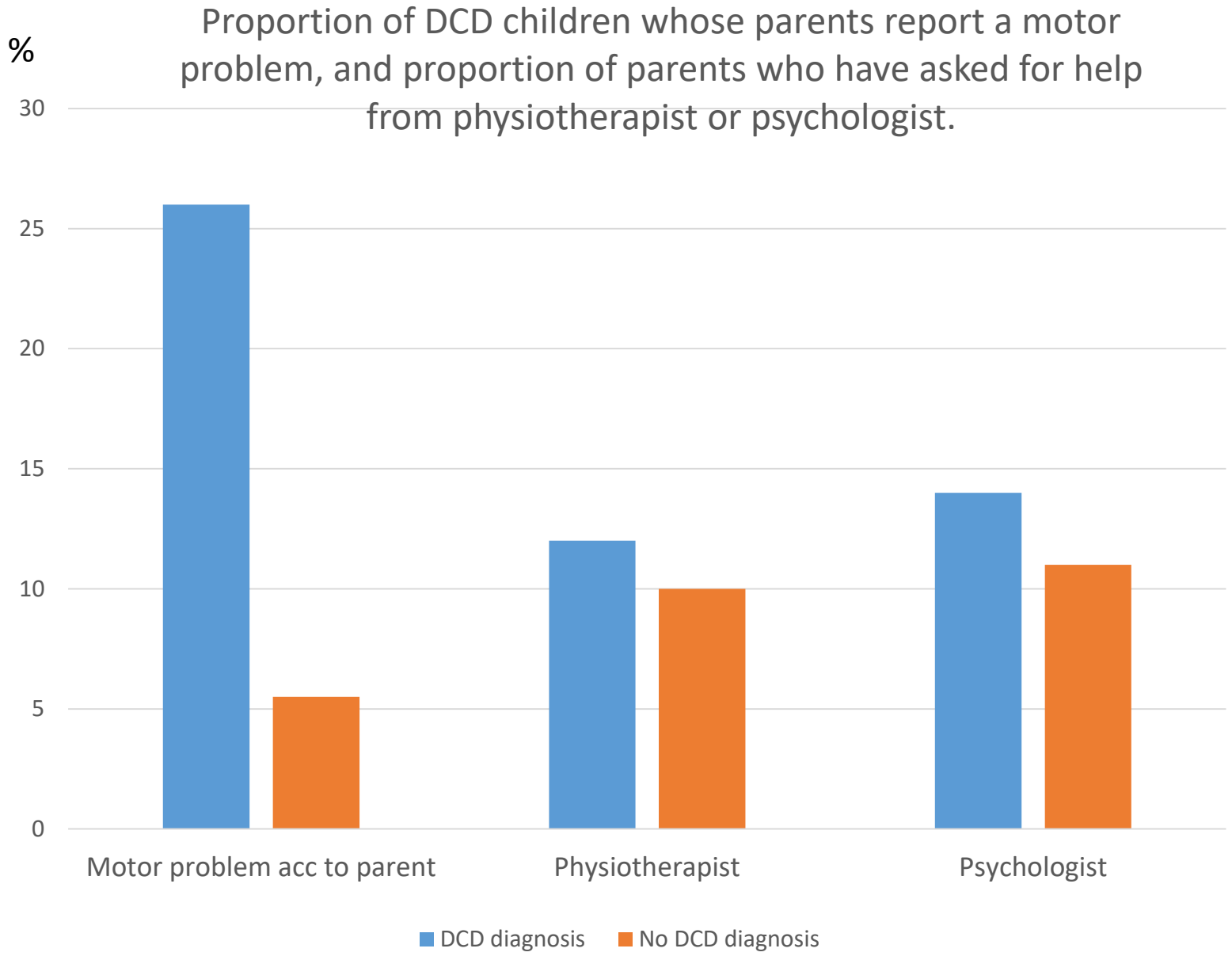


Answer to the third question (a)



Answers to third question (b)




Proportion of DCD children whose parents report a motor problem, and proportion of parents who have asked for help from physiotherapist or psychologist.
%
30
25
20
15
10
5
0
Motor problem acc to parent
Physiotherapist
Psychologist
DCD diagnosis
No DCD diagnosis

EXPRESS
Extremely Preterm Infants in Sweden Study

To conclude

- DCD is a specific motor developmental disorder.
- Shares features with other neurodevelopmental disorders: High prevalence, male predominance, onset during childhood variable severity, lifelong persistence, academic repercussions, long-term socio-emotional consequences.
- Functional impairments and secondary consequences have impact on quality of life
- Better recognition of DCD across medical and educational sectors is needed to ensure that children reach their potential.
- DCD is underdiagnosed. Diagnosis comes as a relief and – hopefully - gives access to multidisciplinary therapy.

Sofia skriver:

….jag har själv diagnosen DCD och upplever det som jobbigt i vardagliga situationer.

….att skriva t.ex. kräver stort fokus…många delar av kroppens muskler måste vara aktiva samtidigt som hjärnan måste tänka ut vad man skall skriva….det är inte automatiserat.

….eftersom jag också har ADHD och Asperger blir jag snabbt trött.
….jag måste tänka på att lyfta benen när jag går i en trappa, fokusera så att foten hamnar rätt….tänka på hur mycket tyngd skall läggas på de olika benen.
…eftersom min hjärna inte har koll på vad min kropp gör blir musklerna spända…

….känt mig korkad och dum eftersom jag inte klarat av vad mina klasskamrater gjorde….mina lärare visste inte hur de skulle bemöta mig.

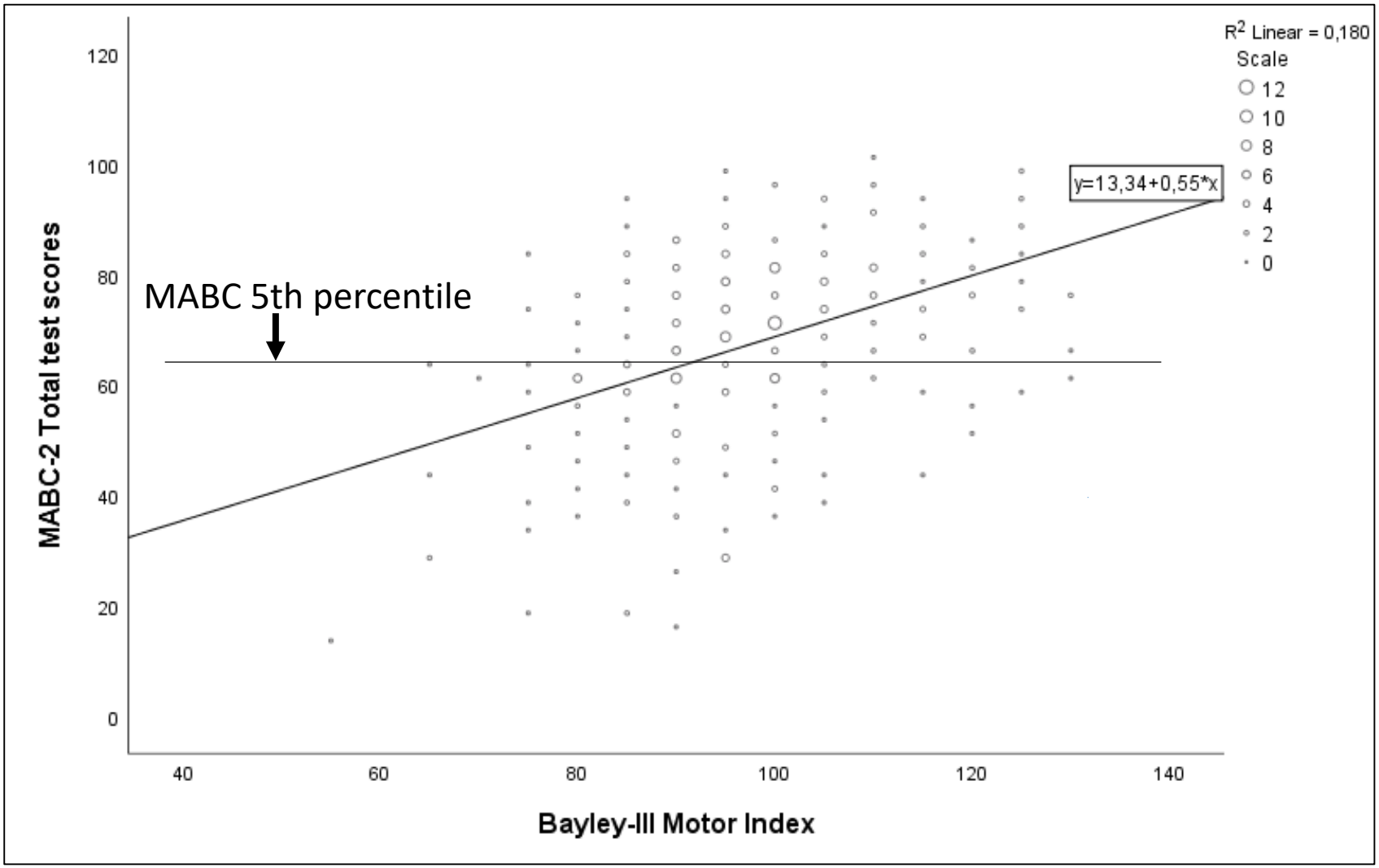
….kan jag verkligen det här…rädslan sätter stopp.

….jag säger till alla er som är som jag: Du är inte dum, din hjärna behöver bara mer tid att förstå….du kan klara precis vad du vill även om vägen dit kan kännas jobbig.

Thank you for your attention

I want to thank all members of the EXPRESS study group for their dedication to the Study.

The predictive value of the Bayley-III for the MABC-2 outcome



The predictive value of the Bayley-III for the MABC-2 outcome

280 children born extremely preterm.
No vision, hearing, problems or CP but Intellectual disability included

Ability of **Bayley-III Motor Index** at 2.5 years corrected age to predict **MABC-2** at age 6.5 years?

Predictive values at Bayley-III score 85 were: sensitivity 26 %, specificity 93%, positive predictive value 50% and negative predictive value 80%.

-

a) Area under the curve 0.706 (p<0.001, 95% CI 0.63-0.78)