## Early Childhood Developmental-Behavioral Screening in Scandinavia & the USA



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## Comparative use of the Ages and Stages Questionnaires in the USA and Scandinavius: a systematic review EVIN P MARCE (\*\*) INNA MASSEN 5.00 (\*\*) PIKLIP WILLIAM\*\* EVIN P MARCE (\*\*) INNA MASSEN 5.00 (\*\*) PIKLIP WILLIAM\*\* I Represent Phatman Parameters Marind drove, Equin C, (5.6.1 & March Ages and Comparative Comparat

#### **Our Systematic Review's Objectives**

- 1) How do different developed countries (the United States, Denmark, Norway and Sweden) use the same two parent-centered, developmental-behavioral screening tools, the Ages & Stages Questionnaire (ASQ) and ASQ:Social-Emotional (ASQ:SE) in children from birth through five years?
- 1) What is known about the effectiveness, feasibility, implementation, considerations for at-risk populations, follow-up steps and research gaps of universal ASQ/ASQ:SE screening?

## Previous reviews involving the ASQ and ASQ:SE

- A systematic review was published about the ASQ's psychometric properties at 2 to 2.5 years (Velikonja et al, 2016)
- A narrative review was published about the use of the ASQ in low & middle-income countries or LMICs (Small, Hix-Small, Vargas-Baron, Marks 2018, Developmental Medicine & Child Neurology, in press).

#### Why focus on the ASQ & ASQ:SE?

- These 2 standardized & validated screens measure a broad-band of developmental-behavioral skills.
- They use parent-report items which allow for "teachable moments" where the process of screening encourages parents to spend "special time" playing with their child.
- They span the birth through 5-year age range.
- They only take 10 to 20 minutes for parents to complete.
- The ASQ and ASQ:SE are "common denominator tools" already being used in Scandinavian and US populations.
- Focusing the review on 1 broad-band developmental and 1 social-emotional screen allows for a more consistent comparison of the "lessons learned" and research opportunities throughout Scandinavia and the USA.

## Systematic Review: Use of the ASQ & ASQ:SE between Scandinavia & the USA

- 6 international databases (Medline/Pubmed, PSYCHInfo, Embase, Cochrane, Cinahl & ERIC) & 3 Scandinavian-specific databases (Christin, Forskningsdatabasen & Diva) were used.
- Key terms used & scope of each search limited to studies conducted on children 0 to 5 years conducted in US, Denmark, Sweden or Norway.
- 3. References for each article were reviewed to identify additional articles.

## Systematic Review: Use of the ASQ & ASQ:SE between Scandinavia & the USA

- 4. One of the lead authors of the ASQ, Dr. Jane Squires, was contacted and her comprehensive list of published ASQ articles was cross checked-against those already identified.
- 5. www.agesandstages.com website also used to identify any published articles that may have been missed. Non-published poster presentations at scientific conferences were likely not included.

## Systematic Review: Use of the ASQ & ASQ:SE in the USA & Scandinavia

- Summary: from 9 databases and 1689 references (published from 1988 to 2018), 127 articles were included and categorized using Covidence online software for systematic reviews.
- The Critical Appraisal Skills Programme (CASP)
   Checklists were used before data-synthesis for all articles that applied to universal ASQ and/or ASQ:SE screening in general or at-risk populations.

#### **Inclusion Criteria**

- 1) For articles using the ASQ, all 5 developmental domains (communication, gross motor, fine motor, problem-solving and personal-social) needed to be reported in order to maintain consistency with the ASQ User Guide's reported psychometric and feasibility properties.
- 2) Articles using other abbreviated versions of the ASQ (e.g. using less than 6 items per domain) and/or ASQ:SE (e.g., haphazardly omitting items that were meant to be scored) were excluded because abbreviated versions are assumed to be psychometrically unsound.

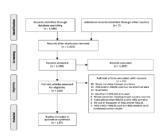
#### **Inclusion Criteria**

- 3) The correct age-interval ASQ and/or ASQ:SE needed to be used. The ASQ and ASQ:SE users' guides and the AAP COFN recommend that the age-adjusted ASQ and/or ASQ:SE be administered for preemies born under 37 weeks gestational age.
- 2) The population under study needed to be exclusively focused on the target countries (Denmark, Sweden, Norway and/or USA) being studied.
- 5) Articles needed to report or discuss empirical data related to the ASQ and/or ASQ:SE.

#### **Excluded Studies**

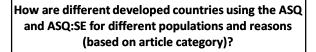
- 39 Wrong country (Not DK, SE, N, or USA)
- 14 Duplicate articles
- 14 ASQ &/or ASQ:SE used but no empirical data
- 11 Did not use of all 5 of the ASQ sub-domains
- 6 Mixed countries (target & outside countries)
- 4 Used abbreviated ASQ subdomains or an abbreviated version of the ASQ:SE
- 2 ASQ &/or ASQ:SE not actually used in study
- 1 ASQ and/or ASQ:SE used but data analysis used combined results (e.g., ASQ & Denver Developmental Materials Screening Test-II results combined)

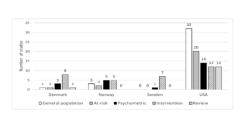
#### **PRISMA Flow Diagram**



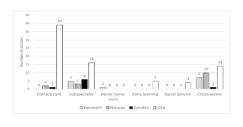
#### **Article Categorization**

- 1) Study about universal screening on a general or an at-risk population
- 2) Psychometric-related study
- 3) Intervention/exposure research study
- 4) Review or policy related study
  - A) Primary care medical setting
  - B) Sub-specialty medical setting
  - C) Nurse home visit setting
  - D) Childcare or early learning/preschool setting
  - E) Social service setting
  - F) Cross-sector setting or birth cohort





What setting is the ASQ and ASQ:SE being used or researched based on country (DK, SV, N or USA)?



#### **Comparative Lessons Learned**

- Unsurprisingly, the USA has the highest number of overall studies (N=90) and highest number of psychometric studies (N=14) for the ASQ & ASQ:SE.
- Most US studies support the ASQ & ASQ:SE as being well standardized, accurate, reliable, lowcost & feasible for use in a busy office setting.
- Most US studies involve universally screening with the ASQ and/or ASQ:SE to detect suspected delays in a primary care medical settings (in either a general or at-risk population).

#### **Comparative Lessons Learned**

- The ASQ and ASQ:SE's "overall" section is being routinely ignored by researchers in both the USA and Scandinavia.
- No studies measured and analyzed the results of the overall section (which are 6 to 9 items on at the end that do not get scored).
- ASQ/ASQ:SE authors should make the ASQ-4
   ASQ:SE-3's overall section measurable.
- It is unclear how parents' responses to the "overall" questions affect the ASQ's and ASQ:SE's validity.

#### Scandinavian Lessons Learned

- In Scandinavia, the ASQ & ASQ:SE has primarily been used to track/monitor DB outcomes over time after a child has had an environmental exposure or a specific intervention (even though the ASQ & ASQ:SE are not diagnostic instruments).
- Few Scandinavian studies are using the ASQ and/or ASQ:SE for its original purpose—i.e., early detection of developmental delays and social-emotional problems in a general or atrisk population.

#### **Scandinavian Lessons Learned**

- Norway had 5 supportive psychometric (norming or validation) studies on the ASQ-2. Psychometric research is needed on the ASQ:SE.
- Denmark had 2 ASQ and 1 ASQ:SE-2 psychometric studies but norming & validation research is needed on UTD versions of the ASQ & ASQ:SE.
- Sweden had 1 ASQ:SE validation study but is lagging behind with ASQ & ASQ:SE research. 7 out of 8 Swedish studies are about tracking developmental risk outcomes related to delayed vs. early umbilical cord clamping.

#### Scandinavian Lessons Learned

- Danish & Norwegian ASQ & ASQ:SE have been officially translated with "back translations" and are commercially available. Swedish ASQ and ASQ:SE has been translated with a "back translation".
- Good DB screens need to be re-normed & validated every 10 years.



- 14 fairly well-done Danish studies have used the ASQ.
- The ASQ & ASQ:SE is commercially available in Danish and is being used in many Danish intervention-based, large cohort studies.
- Danish ASQ and ASQ:SE studies show promise for routine and periodicuse at home visit or "sundhedsplejerske" settings.

#### Scandinavian Lessons Learned

- Norwegian ASQ-2 has been normed & validated but it became out-of-date in 2015.
- Analysing 4 Norweigian population-based samples with the 6-month ASQ showed few relevant clinical differences compared to US samples. Valla et al., Acta Paediatr, 2016



 Janson 2004 study found the Norwegian ASQ-2 had mean domain scores and cut-offs that were comparable to US normative data, although the variation in domain scores tended to be somewhat smaller in the Norwegian sample.

#### Scandinavian Lessons Learned

 1 randomized Norwegian study on a general population found the ASQ mail-back collection strategy to be problematic. ASQ completion rates were higher (76%) in infants and toddlers but unacceptably low (32%) in preschoolers.



 Another lesson from Norway is to routinely and periodically screen mothers for peripartum depression using the EPDS and, when results are positive/concerning, these at-risk children should additionally be screened with the ASQ:SE at age 2 years or younger. Fathers should be screened for depression too!

#### Scandinavian Lessons Learned

- Swedish ASQ & ASQ:SE are for research use only.
- 0 ASQ validation and/or norming studies identified.
- 1 ASQ:SE validation (but no norming) studies identified.



- However, the ASQ and ASQ:SE are being used in 2 large cohort studies in Västerbotten region of Sweden.
- In 2018, after our systematic review was published....



#### **US Evidence & Lessons Learned**

- In US medical settings, developmental-behavioral surveillance is greatly enhanced when medical providers universally & periodically screen general or at-risk populations with the ASQ and/or ASQ:SE.
- A RCT in a US medical setting shows ASQ screening improves the timeline for the early identification of suspected delays, physician-generated referrals to early intervention (EI) & the percentage of children receiving EI services.

#### **US Evidence & Lessons Learned**

- North Carolina's Assuring Better Child Health and Development (ABCD) initiative increased the # of ASQ-2 screenings per child over the first 2-2.5 years of the initiative, which led to earlier El referrals in atrisk children. The % of children receiving El services statewide increased from 3.0% to 4.3%.
- Illinois' Enhancing Developmentally Oriented Primary Care (EDOPC) initiative trained primary care practices to routinely and periodically screen with the ASQ-2 and ASQ:SE in the first 3 years of life. The EDOPC initiative reached its target of screening 85% of patients with the ASQ-2 (in 11/16 practices in children at 1 and 2 years of age) and with the ASQ:SE (in 7/16 practices in children at 18 months of age).

#### **US Evidence & Lessons Learned**

- System-wide care coordination programs and/or a clinician's history and PE should be utilized to hone referral choices (e.g., parenting programs, domestic violence shelters, high-quality daycares or preschools, psychologist, physical therapist, neurologist, etc.) and to ensure that at-risk children get the most appropriate services in a timely manner.
- An integrated model of care (i.e., colocation of early childhood developmental and mental health specialists within medical offices or "Healthy Steps") improves short-term outcomes and more effectively fosters referral and care coordination services.

#### Overall Evidence & Lessons Learned

- General populations: pediatrician impression (surveillance without the use of the ASQ and/or ASQ:SE) fails to timely identify & refer the large majority of children with suspected developmental delays.
- Our review shows that general and at-risk populations "broadly benefited" in many different ways (e.g., increased early detection, referral and EI/ECSE eligibility rates, favorable surveys from parents and physicians, etc.) from ASQ and/or ASQ:SE screening.

#### Overall Evidence & Lessons Learned

- At risk populations: ASQ and/or ASQ:SE screening benefited 14 groups (exposure to peripartum maternal depression, foster care placement, parents not being proficient in country's primary language, homelessness, teen parents, international adoptees, children frequently presenting to emergency rooms, children from military families with a deployed parent, preterm or low birth weight, epilepsy/seizure disorder, complex congenital heart disease, sickle cell disease, cancer, and a positive newborn metabolic screening result that could adversely affect neurodevelopment).
- 1 outlier study found the ASQ did not effectively identify additional domain delays (beyond the communication domain) in children already diagnosed with bilateral sensorineural hearing loss.

#### Can the ASQ help to detect autism?

- If the ASQ-3's communication domain is in the referral or monitoring zones at 18 & 24 mo., then screen with a MCHAT-R/F per the Hardy et al. 2015 JDBP study
- 87% of children who failed the MCHAT-R & 95% of the children diagnosed with autism were in the referral or monitoring zone on the ASQ-3's communication domain at 18 and 24 months.
- Children who passed the MCHAT at 18 mo. but were later diagnosed with ASD often had ASQ delays in the communication, personal-social and fine motor domains at 18 mo. Differences were more pronounced in girls with ASD per Øien et al. Pediatrics. 2018

#### **Overall Evidence & Lessons Learned**

- "All screening programmes do harm; some do good as well, and, of these, some do more good than harm at reasonable cost. The first task of any public health service is to identify beneficial programmes by appraising the evidence." – Muir Gray, 2008
- No studies explicitly investigated harms or provided any evidence that the ASQ and/or ASQ:SE harmed children, families or society.
- 5 studies reported that primary care doctors and parents/caregivers value and learn important new information (about children's strengths and limitations) from the screening process

## Working as a team, we are expected to <u>promptly</u> identify...





US children (≤ 18 years) with any developmental disability (15%), autism (1.7%) or a mental health disorder (11 to 20% in the USA), and other disorders like ADHD (11%).

Scandinavian (specifically Danish) children
11.8% of 8 to 9-year old children have a DSM-V developmental
disability or mental health disorder (and 1.15% have ASD
[Sweden in 2016] and 5% have ADHD [Denmark in 2006])







In the USA, what is the best settings for DB screening?

- 1) Family practitioner & pediatrician clinics (medical sector)
  - 2) Home visit nurses (social-medical service sector)
  - 3) Preschools or kindergartens (education sector)
    - 4) Private and home-based daycares
  - 4) Psychologists or psychiatrists (mental health sector)







In Scandinavia... what are the best settings?

- 1) Home visit nurses (social service-medical sector)
  - 2) General practitioner, community/district health nurse clinics (medical sector)
    - 3) Daycare (vuggestue or dagpleje)
- 4) Preschool & kindergarten (børnehave, education sector)
  - 4) Psychologists or psychiatrists (mental health sector)

### What's Going on in the USA? AAP Developmental Screening Schedule

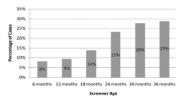




Use a standardized, accurate & reliable, broad-band developmental screen (e.g., ASQ-3 or PEDS +/- PEDS:DM) routinely at 9, 18, 24 or 30 months + as needed from 0 to 5 years From 2017 to 2018, only 30.4% of US children received a parent-reported developmental screening & state-specific variance spanned 40 percentage points (17% Mississippi – 59% Oregon)

## What's Going on in the USA? AAP Social-Emotional Screening Schedule





Use a standardized, accurate & reliable social-emotional screen routinely at 5 years + as needed from 0-4 years. Some U.S. doctors use the ASQ:SE-2 routinely at 4 years to help measure "kindergarten readiness".

(22.4% of children [6-36 mo.] at risk, Briggs et al. Pediatrics, 2012)

### What's Going on in the USA? Example of a Practice's Screening Schedule

SWYC Family Questions: 2 weeks to detect parental tobacco/alcohol/drug use, food insecurity, parental depression & domestic violence

EPDS: 2, 4 & 6 months to detect maternal depression ASQ-3: 6, 9, 12, 24 & 36 months to detect a broad spectrum of developmental delays

ASQ:SE-2: 18 months & 4 years to detect socialemotional problems

M-CHAT-R/F at 18 & 24 months (or if any parent or clinician concerns from 15 to 30 months) to detect autism

#### What's Going on in Scandinavia?

- Sundhedsplejerske (home visit nurses) screen children with different instruments in different municipalities.
- Home visit nurses commonly use more narrow-band, direct, observable screens that are not parent centered.
- In Denmark, home visit nurses (in 39 out of 98 municipalities) screen with the Alarm Distress Baby Scale, which measures social withdrawal behavior (related to parental depression) in children ≤ 2 years.







#### What's Going on in Scandinavia?

- Young children are universally examined by sundhedsplejerske (home visit nurses) and general practitioners (not by pediatricians – who are specialists).
- 93-96% of children 3 to 5 years are enrolled in preschool.
- However, general practitioners & community health nurses are not routinely using high-quality, broad-band developmental & social-emotional screening.







#### What's Going on in Scandinavia?

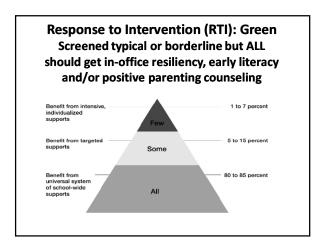
- Young children are universally screened for language delays at 2.5 to 3 years in preschools, child healthcare centers or, less commonly, general medical practices.
- Screening is being done the end of the critical first 1,000 days of life (900 to 1,100 days of life or later).
- Isn't screening being done too late in Scandinavia?
- Why isn't Scandinavia screening all developmental domains, including the social-emotional domain?



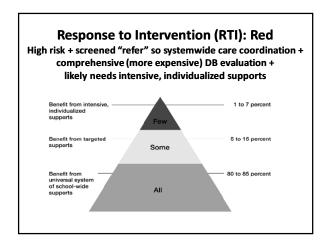




## Follow-up Steps Coordinating and checking/verifying processes between the medical, educational, social and mental health sectors Coordinating and checking/ verifying processes Coordinating and checking/ verifying processes Coordinating and checking/ verifying processes



# Response to Intervention (RTI): Yellow Screened "refer" so systemwide care coordination + mid-level (less expensive) DB assessment + will likely need targeted supports Benefit from intensive, individualized supports Benefit from targeted supports Some Benefit from targeted supports Some Benefit from targeted supports All



#### **Centralized Care Coordination**

"is the deliberate organization of patient care activities between 2 or more participants (including the patient/family) involved in a patient's care to facilitate the appropriate delivery of health care services."



## Centralized resource list for at-risk and high-risk children 0-5 years

- 1. High-quality daycare, preschool and kindergartens
- 2. Positive parenting program (e.g., Incredible Years)
- 3. Early Intervention specialist (more common job in USA)
- Pediatricians (but are they are not all comfortable managing children with DB disabilities & disorders in DK/N/SV)
- 5. Speech and language pathologists
- 5. Pediatric physical or occupational therapists
- 7. Pediatric psychologists and/or psychiatrists
- 8. Pediatric neuropsychiatrist or neurologist
- 9. Developmental disability, genetic/metabolic sub-specialists

## Centralized resource list for parents of at-risk or high-risk children 0-5 years

- 1. Positive parenting program (e.g., Incredible Years or Triple P: Positive Parenting Program)
- 2. Social worker to support the family's practical needs
- 3. Language classes for immigrant parents
- Psychologist and/or psychiatrist for the parent(s) –
   Does the parent need trauma-related counseling due to a history of adverse childhood experiences (ACEs)?
- 5. Domestic violence shelter
- 6. Alcohol or drug abuse rehabilitation program



#### "EARLY INTERVENTIONERS ASSEMBLE!"

The "endgame" is for policy makers, doctors, nurses, daycare providers, educators, social workers & mental health professionals to work together as a team!