



Topic Expert Group: Follow-up and continuing care

Meeting special needs at school

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Target group

Infants born very preterm or those infants with risk factors (see preamble TEG Follow-up & continuing care) and parents

User group

Healthcare professionals, education professionals, neonatal units, hospitals, follow-up teams, and health services.

Statement of standard

Developmental progress and school readiness of infants born very preterm or with risk factors are assessed 6-12 months prior to initial entry into formal schooling, and education professionals receive training about the potential special educational needs of children born very preterm or with risk factors.

Rationale

The goals are to (i) evaluate school readiness prior to initial entry into formal schooling to inform educational provision and support, and (ii) provide information and training to education professionals in order to increase their awareness and knowledge of how to support the learning of children with developmental problems and disorders associated with perinatal risk.

Very preterm children or those with additional neonatal risk factors have an increased risk for poor academic attainment, learning difficulties, and special educational needs. (1–6) Neuropsychological sequelae include poor attentional (7,8) and inhibitory control (9), slower processing speed (10), problems with fine motor skills and visual-motor integration (11), deficits in executive function and working memory (12,13), general cognitive impairments (14,15), language problems (16), and difficulties with sensory processing (17). These cognitive abilities are important prerequisites for learning. (18) Deficits in these areas may limit children's abilities to profit from formal instruction in all school subjects, and particularly in mathematics. (2,19–22) Children's social and emotional difficulties (23,24) may also impact their attainment at school (see TEG Follow-up & continuing care).

While parents and teachers often expect developmental catch-up with peers, studies show that the cognitive and academic difficulties of very preterm children persist throughout adolescence and adulthood. (25–29) In particular, teachers lack knowledge and formal training about preterm children's educational needs and how to facilitate their learning. (30) Thus, teachers need to be informed about the specific constellation of problems experienced by very preterm children. Early identification and individually tailored support may help children achieve their full academic potential. (31)



Benefits

Short-term benefits

N/A

Long-term benefits

- Early identification of children at risk for learning difficulties (1,32–34)
- Timely development of an individualised education plan and initiation of intervention for children with developmental problems or poor school readiness (consensus)
- Informed decisions about educational provision (consensus)
- Increased provision of training for education professionals (about the special educational needs of some very preterm children) (consensus)
- Potentially improved educational outcomes and life chances (consensus)
- Improved quality of life for preterm children and their families (consensus)
- Informed parental counselling and participation in educational decision making (consensus)
- Improved communication between parents, teachers, and healthcare professionals (with parental consent) (consensus)

Components of the standard

Component	Grading of evidence	Indicator of meeting the standard
For parents and families		
1. Parents are informed by healthcare professionals about long-term developmental and educational outcomes of children born very preterm and invited to attend a follow-up programme, which includes screening for school readiness, 6-12 months prior to primary school entry, as well as screening for attention, cognitive, motor, and social-emotional problems, and deficits in early academic skills. (1,25–28,33–36)	A (High quality) B (High quality)	Patient information sheet
2. Parents receive standardised feedback about the results of their child’s assessment in a language that is accessible to them, and they are informed about relevant educational policies (e.g., regarding school starting age). (37)	B (Moderate quality)	Parent feedback, patient information sheet
3. Parents of children identified at risk for developmental problems or poor school readiness are offered support prior to school entry, and throughout	A (Moderate quality) B (Moderate quality)	Guideline, parent feedback



schooling. (31)

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| 4. Parents are asked for consent to share the results of their child's screening and/or developmental tests with their school upon entry. (38) | B (High quality)
C (High quality) | Parent consent |
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For education/healthcare professionals

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| 5. A guideline on screening for developmental problems and poor school readiness, (e.g. attention, cognitive, social-emotional, early academic skills, and sensory processing) carried out 6-12 months prior to school entry is adhered to by all responsible professionals. (8–10,13,15,38) | A (High quality)
B (High quality) | Guideline |
| 6. Training on standardised screening for developmental problems and poor school readiness is attended by all responsible professionals. | B (High quality) | Training documentation |

For neonatal unit, hospital, and follow-up team

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| 7. A unit guideline on screening for developmental problems and school readiness is available and regularly updated. | B (High quality) | Guideline |
| 8. Training on standardised screening for developmental problems and poor school readiness is ensured. | B (High quality) | Training documentation |

For health and education services

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| 9. A national guideline on screening for developmental problems and school readiness is available and regularly updated. | B (High quality) | Guideline |
| 10. Pathways and a legal framework are established for obtaining parental consent and sharing of information between health and education services. | C (High quality) | Information sharing protocol and legal guidelines |



Further development	Grading of evidence
For parents and family	
<ul style="list-style-type: none">• Provide funding for disadvantaged families to participate in screening services. (39–41)• Provide resources to encourage parents to participate in their child's educational support planning. (39–41)	A (High quality)
For education/healthcare professionals	
<ul style="list-style-type: none">• Develop teaching methods and strategies that help provide tailored support for very preterm children in the classroom. (30)	A (High quality)
For neonatal unit, hospital, and follow-up team	
N/A	
For health services	
<ul style="list-style-type: none">• Establish system for data sharing between education and health providers.	B (High quality)

Getting started

Initial steps

For parents and family

- Parents are informed by healthcare professionals about the importance of developmental screening and assessment, and the sharing of information with schools and education professionals.

For education/healthcare professionals

- Define what school readiness entails according to national or regional policies and identify age-appropriate screening tools or formal tests.
- Attend training on standardised screening for developmental problems and poor school readiness (professionals providing follow-up and screening services).
- Attend training on providing feedback and advice on educational needs.

For neonatal unit, hospital, and follow-up team

- Develop and implement a guideline on screening for developmental problems and school readiness.
- Develop information on follow-up including developmental screening and assessment of school readiness for parents.
- Establish a clinical pathway from discharge to screening at 6-12 months prior to school entry.

For health service

- Develop and implement a national guideline on screening for developmental problems and school readiness.
- Initiate data linkage between health and education service providers.
- Explore legal guidelines and parental consent framework.



Sources

1. MacKay DF, Smith GCS, Dobbie R, Pell JP. Gestational Age at Delivery and Special Educational Need: Retrospective Cohort Study of 407,503 Schoolchildren. Lau TK, editor. PLoS Med. 2010 Jun 8;7(6):e1000289.
2. Johnson S, Hennessy E, Smith R, Trikick R, Wolke D, Marlow N. Academic attainment and special educational needs in extremely preterm children at 11 years of age: the EPICure study. Arch Dis Child - Fetal Neonatal Ed. 2009 Jul 1;94(4):F283-9.
3. Clark CAC, Fang H, Espy KA, Filipek PA, Juranek J, Bangert B, et al. Relation of neural structure to persistently low academic achievement: a longitudinal study of children with differing birth weights. Neuropsychology. 2013 May;27(3):364-77.
4. Espy KA, Fang H, Charak D, Minich N, Taylor HG. Growth mixture modeling of academic achievement in children of varying birth weight risk. Neuropsychology. 2009 Jul;23(4):460-74.
5. Schermann L, Sedin G. Cognitive function at 10 years of age in children who have required neonatal intensive care. Acta Paediatr Oslo Nor 1992. 2004 Dec;93(12):1619-29.
6. Luu TM, Ment LR, Schneider KC, Katz KH, Allan WC, Vohr BR. Lasting effects of preterm birth and neonatal brain hemorrhage at 12 years of age. Pediatrics. 2009 Mar;123(3):1037-44.
7. Bora S, Pritchard VE, Chen Z, Inder TE, Woodward LJ. Neonatal cerebral morphometry and later risk of persistent inattention/hyperactivity in children born very preterm. J Child Psychol Psychiatry. 2014 Jul;55(7):828-38.
8. Anderson PJ, De Luca CR, Hutchinson E, Spencer-Smith MM, Roberts G, Doyle LW, et al. Attention problems in a representative sample of extremely preterm/extremely low birth weight children. Dev Neuropsychol. 2011;36(1):57-73.
9. Jaekel J, Eryigit-Madzwamuse S, Wolke D. Preterm Toddlers' Inhibitory Control Abilities Predict Attention Regulation and Academic Achievement at Age 8 Years. J Pediatr. 2016 Feb;169:87-92.e1.
10. Mulder H, Pitchford NJ, Marlow N. Processing speed and working memory underlie academic attainment in very preterm children. Arch Dis Child Fetal Neonatal Ed. 2010 Jul;95(4):F267-272.
11. Geldof CJA, van Wassenaer AG, de Kieviet JF, Kok JH, Oosterlaan J. Visual perception and visual-motor integration in very preterm and/or very low birth weight children: a meta-analysis. Res Dev Disabil. 2012 Apr;33(2):726-36.
12. Aarnoudse-Moens CSH, Smidts DP, Oosterlaan J, Duivenvoorden HJ, Weisglas-Kuperus N. Executive function in very preterm children at early school age. J Abnorm Child Psychol. 2009 Oct;37(7):981-93.
13. Anderson PJ, Doyle LW, Victorian Infant Collaborative Study Group. Executive functioning in school-aged children who were born very preterm or with extremely low birth weight in the 1990s. Pediatrics. 2004 Jul;114(1):50-7.
14. Rose SA, Feldman JF, Jankowski JJ, Van Rossem R. Basic Information Processing Abilities at 11 years Account for Deficits in IQ Associated with Preterm Birth. Intelligence. 2011 Jul;39(4):198-209.
15. Wolke D, Strauss VY-C, Johnson S, Gilmore C, Marlow N, Jaekel J. Universal gestational age effects on cognitive and basic mathematic processing: 2 cohorts in 2 countries. J Pediatr. 2015 Jun;166(6):1410-1416-2.
16. van Noort-van der Spek IL, Franken M-CJP, Weisglas-Kuperus N. Language functions in preterm-born children: a systematic review and meta-analysis. Pediatrics. 2012 Apr;129(4):745-54.



17. Geldof CJ, Oosterlaan J, Vuijk PJ, de Vries MJ, Kok JH, van Wassenaer-Leemhuis AG. Visual sensory and perceptive functioning in 5-year-old very preterm/very-low-birthweight children. *Dev Med Child Neurol*. 2014 Sep;56(9):862–8.
18. Jaekel J, Baumann N, Wolke D. Effects of Gestational Age at Birth on Cognitive Performance: A Function of Cognitive Workload Demands. *PLOS ONE*. 2013 May 24;8(5):e65219.
19. Johnson S, Wolke D, Hennessy E, Marlow N. Educational outcomes in extremely preterm children: neuropsychological correlates and predictors of attainment. *Dev Neuropsychol*. 2011;36(1):74–95.
20. Simms V, Cragg L, Gilmore C, Marlow N, Johnson S. Mathematics difficulties in children born very preterm: current research and future directions. *Arch Dis Child Fetal Neonatal Ed*. 2013 Sep;98(5):F457-463.
21. Simms V, Gilmore C, Cragg L, Clayton S, Marlow N, Johnson S. Nature and origins of mathematics difficulties in very preterm children: a different etiology than developmental dyscalculia. *Pediatr Res*. 2015 Feb;77(2):389–95.
22. Jaekel J, Wolke D. Preterm birth and dyscalculia. *J Pediatr*. 2014 Jun;164(6):1327–32.
23. Ritchie K, Bora S, Woodward LJ. Social development of children born very preterm: a systematic review. *Dev Med Child Neurol*. 2015 Oct;57(10):899–918.
24. Heuser KM, Jaekel J, Wolke D. Origins and Predictors of Friendships in 6- to 8-Year-Old Children Born at Neonatal Risk. *J Pediatr*. 2018 Feb;193:93–101.e5.
25. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Attention problems in very preterm children from childhood to adulthood: the Bavarian Longitudinal Study. *J Child Psychol Psychiatry*. 2016 Feb;57(2):132–40.
26. Breeman LD, Jaekel J, Baumann N, Bartmann P, Wolke D. Preterm Cognitive Function Into Adulthood. *Pediatrics*. 2015 Sep;136(3):415–23.
27. Litt JS, Gerry Taylor H, Margevicius S, Schluchter M, Andreias L, Hack M. Academic achievement of adolescents born with extremely low birth weight. *Acta Paediatr Oslo Nor* 1992. 2012 Dec;101(12):1240–5.
28. Basten M, Jaekel J, Johnson S, Gilmore C, Wolke D. Preterm birth and adult wealth mathematics skills count. *Psychol Sci*. 2015;956797615596230.
29. Linsell L, Johnson S, Wolke D, O'Reilly H, Morris JK, Kurinczuk JJ, et al. Cognitive trajectories from infancy to early adulthood following birth before 26 weeks of gestation: a prospective, population-based cohort study. *Arch Dis Child*. 2018 Apr;103(4):363–70.
30. Johnson S, Gilmore C, Gallimore I, Jaekel J, Wolke D. The long-term consequences of preterm birth: what do teachers know? *Dev Med Child Neurol*. 2015 Jun;57(6):571–7.
31. van Veen S, Aarnoudse-Moens CSH, Oosterlaan J, van Sonderen L, de Haan TR, van Kaam AH, et al. Very preterm born children at early school age: Healthcare therapies and educational provisions. *Early Hum Dev*. 2018 Feb;117:39–43.
32. Doyle LW, Anderson PJ, Battin M, Bowen JR, Brown N, Callanan C, et al. Long term follow up of high risk children: who, why and how? *BMC Pediatr*. 2014 Nov 17;14:279.
33. Quigley MA, Poulsen G, Boyle E, Wolke D, Field D, Alfirevic Z, et al. Early term and late preterm birth are associated with poorer school performance at age 5 years: a cohort study. *Arch Dis Child Fetal Neonatal Ed*. 2012 May;97(3):F167-173.



34. Lipkind HS, Slopen ME, Pfeiffer MR, McVeigh KH. School-age outcomes of late preterm infants in New York City. *Am J Obstet Gynecol.* 2012 Mar;206(3):222.e1-6.
35. Reimann M, Hüning B. Frühchen-App entlastet Eltern und Pflegende. *Pflegezeitschrift.* 2017 May 1;70(5):27–9.
36. Hüning BM, Reimann M, Beerenberg U, Stein A, Schmidt A, Felderhoff-Müser U. Establishment of a family-centred care programme with follow-up home visits: implications for clinical care and economic characteristics. *Klin Pädiatr.* 2012 Nov;224(7):431–6.
37. Jaekel J, Strauss VY-C, Johnson S, Gilmore C, Wolke D. Delayed school entry and academic performance: a natural experiment. *Dev Med Child Neurol.* 57(7):652–9.
38. REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation).
39. Eryigit Madzwamuse S, Baumann N, Jaekel J, Bartmann P, Wolke D. Neuro-cognitive performance of very preterm or very low birth weight adults at 26 years. *J Child Psychol Psychiatry.* 2015 Aug;56(8):857–64.
40. Kißgen R, Carlitscheck J, Rapp C, Franke S. [Psychosocial care in institutional neonatology in Germany: a quantitative-empirical inventory from the medical professionals' perspective]. *Z Geburtshilfe Neonatol.* 2012 Dec;216(6):259–68.
41. Kane J, Riddell S, Banks P, Baynes A, Dyson A, Millward A, et al. Special educational needs and individualised education programmes: issues of parent and pupil participation. *Scott Educ Rev.* 2003;(35):38–48.

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Lifecycle

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