Spina Bifida Service Guidelines

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The aim of this document is to provide practical guidance for health professionals to provide services for children with Spina Bifida throughout their life span based on research and evidence to date.

	Services Input	Recommended input
Prenatal	Meet with Consultant Neurosurgeon and Spina Bifida Nurse	• Written information provided. • Discussion regarding medical findings. • Counselling provided to parents.
New born	Temple street Spina Bifida Physiotherapist, Occupational Therapist, Paediatrician,	• Closure of Spine. • Urological assessment, imaging and introduction of catheterisation. • Parent Education regarding Hydrocephalus, latex allergies. • Muscle scoring post-surgery. • Upper and Lower Limb assessment and intervention when required. • Discussion regarding ambulatory potential – completed by Consultant Orthopaedic Surgeon and/or Physiotherapist. • Parents have option to avail of Neonatal Behavioural Assessment Scale assessment. • Introduction of postural management- positioning and play program. • Advice regarding car seat, sleeping, buggy and or pram. • Referral to local Early intervention Team or Primary care services completed with parents' consent. • Routine Immunisations.
Infant <1 year	• Enrolled in Early Intervention Team (EIT)	• Ongoing urological assessment and imaging with interventions as necessary. • Parent education regarding postural management and equipment. • Parent education on how to support the development of play, motor, cognitive and process skills. • Developmental assessment with the Bayley III or Griffiths as necessary. • Adaptive behaviour skills assessment with the ABAS-3 or Vineland 3 as necessary. • Upper and lower limb management including

		stretching to maintain movement, improve function when possible and prevent contractures. • Annual individual and family service plan clearly outlining goals of therapy. • Coaching parents to become active participants in therapy sessions – shifting focus of frequency of therapy sessions. • Parents/siblings receive adequate information and support. • Parental discussion regarding ambulatory potential both from the primary therapist and Spina Bifida team. • Spina Bifida clinic review twice within the child's first year (pre liaison forms highlighting goals and areas of concern are completed by local Early intervention team).
Toddler 1-3 years	• Early intervention Team	• Developmental assessment with the Bayley III or Griffiths between 12 and 30 months. • Cognitive assessment with the WPPSI-IV from 30 months onwards. • Adaptive behaviour skills assessment with the ABAS-3 or Vineland 3 from 12 months onwards. • The above to be completed by the child's local Early Intervention Team. • Ongoing urological assessment and imaging with interventions as necessary. • Wheelchair assessment between 18 to 24 months or when a child can sit independently. • Education regarding postural management and sensation. • Equipment to support 24 hour management including specialised buggy/ wheelchair, activity chair and or sleep system where required. • Assist with transition to preschool – this may involve environmental assessment, preschool assistance support, sharing how to support child's participation in preschool activities. • Annual meeting with child and family to agree goals and outline intervention to address same (written copy to be sent to SB team with parent's consent).

		• Reviewed annually by the Spina Bifida team in TSCUH (pre liaison forms and phone calls completed with local team prior to clinic).
Preschool 3-5 years	• Early intervention services	• Ongoing urological assessment and imaging with interventions as necessary. • Cognitive assessment using the WISC-V & WIAT-III, prior to transition to school and strategies outlined on how to support a child's learning in school. • Adaptive behaviour skills assessment with the ABAS-3 or Vineland. • Parent and teacher education regarding the neuropsychological pattern of strengths and weaknesses associated with Spina Bifida especially SB Myelomeningocele and the potential impact on learning and social skills. • Consultation with the Neuropsychologist with the Spina Bifida Service as necessary available to parents, teachers and the child's local team. • Enrolled in preschool or school program pending on age of child and liaise with AIMS. • Occupational therapy assessment of preschool/ school environment and recommendation on how to support accessibility and toileting. • Occupational therapy recommendations on how to support participation in preschool or school activities such as prewriting, handwriting, copying from the whiteboard, playing with friends and playing games in school. • Assessment of Play skills and recommendations on how to enhance same. • Application for SNA and resource hours. • Parents to train SNA in health needs of child including catheterisation. • Adequate equipment provided for toileting e.g. commode, flamingo, swan, rifton. • Education regarding postural management and sensation. • Equipment to support 24 hour management including activity chair, wheelchair and or sleep system where required. • Wheelchair obtained for mobility & transport if appropriate. • Wheelchair skills training and transfers training. • Discussion regarding ambulatory potential from primary team and SB team. • Annual meeting with child and family to agree

		goals and outline intervention to address same (written copy to be sent to SB team). • Lower limb management including stretching to maintain movement, improve function when possible and prevent contractures. • Reviewed annually by the Spina Bifida team in TSCUH (pre liaison forms and phone calls completed with local team prior to clinic).
School age	• School Age team	• Promotion of Independent living skills – parents document how much time they spend with their child or doing for their child. • Ongoing urological assessment and imaging with interventions as necessary. • Psychoeducational assessment in 1st class to include IQ, educational attainments and adaptive behaviour skills to be conducted by the local team psychologist. It is recommended that the WISC-V, WIAT-III and ABAS-3/Vineland are administered. • Specialist neuropsychological assessment of memory, attention and executive functioning to be conducted by the Senior Clinical. Neuropsychologist with the Spina Bifida Team following the psychoeducational assessment. • Parent and teacher education regarding the individual neuropsychological pattern of strengths and weaknesses associated with Spina Bifida especially SB Myelomeningocele and the potential impact on learning and social skills. • Consultation with the Neuropsychologist with the Spina Bifida Service as necessary available to parents, teachers and the child's local team. • Complete Fun Friends program or Friends for life program (school based anxiety prevention and resilience programs funded through the department of education). • Occupational therapy assessment and intervention strategies to support participation in everyday meaningful activities. • Education regarding postural and skin care management. • Equipment to support 24 hour management including activity chair, wheelchair, and or sleep system where required. • Wheelchair skills training and transfers training. • Wheelchair review annually or as required. • Annual meeting with child and family to agree goals and outline intervention to address

		same (written copy to be sent to SB team) • Lower limb management including stretching to maintain movement, improve function when possible and prevent contractures. • Child takes an active role in therapeutic interventions. • Prepare for transition to secondary school. • Psychoeducational assessment at the end of 5th class/beginning of 6th class to include IQ, educational attainments and adaptive behaviour skills to be conducted by the local team psychologist. It is recommended that the WISC-V, WIAT-III and ABAS-3/Vineland 3 are administered. • Specialist neuropsychological assessment of memory, attention and executive functioning to be conducted by the Senior Clinical Neuropsychologist with the Spina Bifida Team following the psychoeducational assessment. • Parent and teacher education regarding the individual neuropsychological pattern of strengths and weaknesses associated with Spina Bifida especially SB Myelomeningocele and their potential impact on learning and social skills. • Consultation with the Neuropsychologist with the Spina Bifida Service as necessary available to parents, teachers and the child's local team. • Child is knowledgeable about Spina Bifida management & prevention of complications • Parents and child have the option to engage with voluntary bodies such as Spina bifida Ireland, IWA etc. • Annual Medical review by local Paediatrician consider nutrition, BMI, bone health, pubertal status. • Reviewed annually by the Spina Bifida team in TSCUH (pre liaison with local teams prior to clinic).

Adolescent		- Ongoing urological assessment and imaging with interventions as necessary. - Review Independent living skills and participation in meaningful activities. - Cognitive or Neuropsychological assessment to address educational & vocational needs, including assessment of readiness to transition skills prior to transitioning to adult services. - Assessment of emotional well-being as necessary by local services. - Receives adequate education & vocational service & information/supportive services. - Participates in adaptive drivers education course. - Understands folic acid supplementation. - Aware of sexual issues. - Prevention of sexual misuse/abuse expands. - Knowledgeable about Spina Bifida management & prevention of complications. - Annual Medical review by local Paediatrician consider nutrition, BMI, bone health, pubertal status.