

## Editorial

---

# Preface to the special issue for the guidelines for the care of people with spina bifida

Brad E. Dicianno<sup>a,b,\*</sup>, Nienke Dosa<sup>c</sup> and Patricia Beierwaltes<sup>d</sup>

<sup>a</sup>*Spina Bifida Association, Arlington, VA, USA*

<sup>b</sup>*Department of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA*

<sup>c</sup>*Department of Pediatrics, SUNY Upstate Medical University, Syracuse, NY, USA*

<sup>d</sup>*School of Nursing, Minnesota State University e Mankato, Mankato, MN, USA*

**Abstract.** “*Guidelines for the Care of People with Spina Bifida*” provide the best, most up-to-date recommendations for care across the lifespan, from newborn to adult. This special issue of the *Journal of Pediatric Rehabilitation Medicine* is a collection of key sections of the 2018 *Guidelines*. The sections of the *Guidelines* published herein have been expanded from their original format to include more background information about key topics and why they are important in the care of people with SB. It is the hope of SBA that these and future *Guidelines* will promote and standardize best practice regardless of the characteristics of individuals with SB or where their care was received. It is through providing better care that we will ultimately achieve a better future for all those living with SB.

**Keywords:** Spina bifida, spinal dysraphism, case management, standards

Spina Bifida is the most commonly occurring complex congenital birth defect associated with long-term survival. The Spina Bifida Association (SBA) is the only national voluntary health agency solely dedicated to serving people affected by Spina Bifida (SB). Its mission is to build a better and brighter future for all those impacted by SB. The SBA, through a cooperative agreement with the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in the Centers for Disease Control and Prevention (CDC), has created the Spina Bifida Collaborative Care Network (SBCCN). The SBCCN plays a vital role in improving the health of people with SB across their lifespan by assessing their needs, connecting health care providers, recognizing clinics with the best outcomes, and identifying

research priorities. A major initiative of the SBCCN is to update and expand healthcare guidelines relevant to SB.

“*Guidelines for the Care of People with Spina Bifida*,” was published on the SBA website in 2018 [1]. The development of the 2018 *Guidelines* was the culmination of three years of planning and work. New *Guidelines* were needed to ensure that people with SB receive the best, most up-to-date care possible and that emphasis was placed on the continuum of care across the lifespan, from newborn to adult. A number of new topics were added to promote health, well-being and quality of life. The work to produce the 2018 *Guidelines* involved over 100 international experts using evidenced based-research and consensus methodologies [2].

This special issue of the *Journal of Pediatric Rehabilitation Medicine* is a collection of key sections of the 2018 *Guidelines*. The sections of the *Guidelines* published herein have been expanded from their original

---

\*Corresponding author: Brad E. Dicianno, Department of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine, 6425 Penn Ave., Suite 400, Office 4115, Pittsburgh, PA, 15206, USA. Tel.: +1 412 822 3700; E-mail: Dicianno@pitt.edu.

format to include more background information about key topics and why they are important in the care of people with SB. Other sections have been published separately [3,4].

Advances in models of health care delivery have improved the lives of children with medical complexity, including those with SB. Patient- and family-centered care coordination, in particular, is a critical component of these services [5]. Care coordination is not the primary responsibility of a single practitioner; rather, all practitioners who interact with patients and families have a role to play [6]. Thus, care for people with SB often involves a “medical neighborhood” [7] and is “team-based” [8]. While many recommendations in the *Guidelines* fall within the scope of practice in a “Spina Bifida Clinic,” optimal care is best achieved as a partnership among people with SB and their families, primary care providers, and specialists along with the larger health systems and community-based organizations. Also, quality of care is improved when there is a process to transition young adults with SB safely from pediatric to adult services [9]. The SBA supports and recommends the multidisciplinary clinic model as a way to deliver coordinated care and services to help transition children to adulthood [10]. However, this model faces significant barriers in many healthcare systems and thus may not be feasible or optimal in all situations. The *Guidelines* were written with this idea in mind and present the best evidence for what care should be delivered, regardless of the model or types of practitioners available. When using the *Guidelines*, it is also important to consider how language, level of acculturation, and social constructs (e.g. concept of self-management and independence from others for care) directly influence the patients’ and families’ understanding of the recommendations provided and how these factors might impact their willingness to change behavior [11].

While the *Guidelines* represent the most up-to-date evidence, research in many areas remains limited, especially with respect to the care of adults. Therefore, the recommendations in these articles represent the collective judgement of expert working groups and are considered options, rather than standards of care. They are not meant to be legal requirements and are intended to provide the practitioner with recommendations based on the current best available research findings and expert consensus.

It is the hope of SBA that these and future *Guidelines* will promote and standardize best practice regardless of the characteristics of individuals with SB or where

their care was received. It is through providing better care that we will ultimately achieve a better future for all those living with SB.

## Acknowledgments

This publication was supported in part by Cooperative Agreement U01DD001077, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official view of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

## Conflict of interest

Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article.

## References

- [1] Spina Bifida Association. Guidelines for the care of people with spina bifida. 2018. <https://www.spinabifidaassociation.org/guidelines/>. Accessed February 3, 2020.
- [2] Dicianno BE, Beierwaltes P, Dosa N, Raman L, Chelliah J, Struwe S, et al. Scientific methodology of the development of the guidelines for the care of people with spina bifida: An initiative of the spina bifida association. *Disabil Health J*. 2020 Apr; 13(2): 100816. doi: 10.1016/j.dhjo.2019.06.005.
- [3] Wiener JS, Frimberger DC, Wood H. Spina bifida health-care guidelines for men’s health. *Urology*. 2018 Jun; 116: 218–226. doi: 10.1016/j.urology.2018.01.005.
- [4] Fremion EJ, Dosa NP. Spina bifida transition to adult health-care guidelines. *J Pediatr Rehabil Med*. 2019; 12(4): 423–429. doi: 10.3233/PRM-190633.
- [5] Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014 May; 133(5): e1451–60. doi: 10.1542/peds.2014-0318.
- [6] Kuo DZ, McAllister JW, Rossignol L, Turchi RM, Stille CJ. Care coordination for children with medical complexity: Whose care is it, anyway? *Pediatrics*. 2018 Mar; 141(Suppl 3): S224–S232. doi: 10.1542/peds.2017-1284G.
- [7] Kuo DZ, Houtrow AJ. Recognition and management of medical complexity. *Pediatrics*. 2016 Dec; 138(6): e20163021. doi: 10.1542/peds.2016-3021.
- [8] Katkin JP, Kressly SJ, Edwards AR, Perrin JM, Kraft CA, Richerson JE, et al. Guiding principles for team-based pediatric care. *Pediatrics*. 2017 Aug; 140(2): e20171489. doi: 10.1542/peds.2017-1489.
- [9] Dicianno BE. 21st century challenges to the provision of

- health care to adults with spina bifida: A rehabilitation approach. *Arch Phys Med Rehabil.* 2014 Sep; 95(9): 1601–2. doi: 10.1016/j.apmr.2014.01.011.
- [10] Thibadeau J, Walker WO, Castillo J, Dicianno BE, Routh JC, Smith KA, et al. Philosophy of care delivery for spina bifida. *Disabil Health J.* 2020 Apr; 13(2): 100883. doi: 10.1016/j.dhjo.2019.100883.
- [11] Olausen SJ, Renzaho AMN. Establishing components of cultural competence healthcare models to better cater for the needs of migrants with disability: A systematic review. *Aust J Prim Health.* 2016; 22(2): 100–112. doi: 10.1071/PY14114.