

## **Press release – embargoed until 00.00hrs 21<sup>st</sup> March 2025**

**21<sup>st</sup> March 2025**

### **World Down Syndrome day – Improve support systems**

The 21<sup>st</sup> March marks an opportunity to raise awareness, overcome misconceptions and educate the public about Down Syndrome which was first described by Dr John Langdon Down in 1862.

Down syndrome is the most common chromosomal condition in the UK. It is estimated there are approximately 40,000 people with Down syndrome in the UK. Approximately 1 in 800 babies born in the UK has Down syndrome.

The theme for 2025 is recognition of the need to improve support for individuals with Down Syndrome and their families. Children's nurses and children's learning disability nurses provide crucial support to families from the time of diagnosis, enabling children and young people to achieve their full potential.

The provision of appropriate and targeted support recognising specific needs is a basic human right as outlined in the Human Rights Act<sup>1</sup>, UN Convention on the Rights of the Child<sup>2</sup> and the UN Convention on the Rights of Persons with Disabilities<sup>3</sup>. Good support provision encompasses:

- Respective legislation and policies
- Inclusion of those with Down Syndrome and their representatives in the design, implementation and monitoring of services to meet their needs
- Information and data to aid service provision planning, including understanding barriers faced and individual support needs.
- Social and community support including specific services and financial benefits to cover disability-related extra costs that individuals and their families face.

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<sup>1</sup> Human Rights Act (1998) <https://www.legislation.gov.uk/ukpga/1998/42/contents>

<sup>2</sup> UN Convention of the Rights of the Child (1989) <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>

<sup>3</sup> UN Convention of the Rights of Persons with Disabilities (2006) See <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>

## The ABPN believes that

- Every child and young person has a right to have their specific needs recognised and addressed<sup>4,5</sup>
- Infants, children and young people should receive care from nurses that have the child specific knowledge, skills and competencies to meet their unique needs in age-appropriate facilities, at home or closer to home in community and general practice settings<sup>6</sup>
- Child field specific pre-registration undergraduate education programmes, as well as specific post registration education is crucial to equip nurses to meet the needs of children and young people across all settings, including at home or closer to home in community and general practice settings<sup>7,8</sup>

“The importance of support for children and young people with Down syndrome and their families is key to helping them to reach their potential. This support needs to be delivered by nurses who are skilled, knowledgeable and able to draw on their expertise and the resources available”

Professor Bernie Carter, President

## Notes for editors

The term child refers to infants, children, young people and young adults up to 25 years of age

The ABPN recognises that primary and community services, as well as child public health and mental health services, including school nurses and health visitors also have a key role in supporting children, young people and families.

The ABPN is a network of children’s nurses with a wide membership of experts in clinical practice, education, leadership and research. It is the oldest children’s nursing association in the world, established in 1938.

[www.abpn-uk.com](http://www.abpn-uk.com)

Blue Sky: @abpn-childnurse.bsky.social

Facebook: Association of British Paediatric Nurses

Tik Tok: @ABPN\_ChildNurse

YouTube: @ABPN\_ChildNurse

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<sup>4</sup> See ABPN Position statement on Children and Young People’s rights

[abpn\\_position\\_statement\\_children\\_and\\_young\\_peoples\\_rights.pdf](#) and ABPN Background briefing on Children and Young People’s Rights [abpn\\_background\\_briefing\\_children\\_and\\_young\\_people.pdf](#)

<sup>5</sup> UN Declaration of Human Rights 1948 see <https://www.un.org/en/about-us/universal-declaration-of-human-rights/>

<sup>6</sup> See ABPN Position statement on Workforce planning and nurse staffing

[abpn\\_position\\_statement\\_workforce\\_planning\\_and\\_nurse\\_staffing-final\\_nov\\_2024.docx](#) and ABPN Background briefing on workforce planning and nurse staffing [abpn\\_workforce\\_planning\\_and\\_nurse\\_staffing\\_background\\_briefing\\_paper-final\\_nov\\_2024.docx](#)

<sup>7</sup> See ABPN Position Statement on Children’s Nurse Education

[abpn\\_position\\_statement\\_nurse\\_education\\_final\\_24\\_november\\_2024.pdf](#)

<sup>8</sup> See ABPN Background Paper on Children’s Nurse Education

[abpn\\_cn\\_education\\_background\\_paper\\_final\\_22nd\\_november\\_2024.pdf](#)