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Dear Sir/Madam

Re: Consultation on Foundational Supports for children under 9 with developmental concern, delay and/or disability, families and carers

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We do this through raising awareness, empowering health professionals to deliver high quality, best-practice care to stroke patients, facilitating research, and supporting survivors of stroke. We advocate for better systems, processes and resources to help health professionals deliver world class stroke care.

Up to 120 babies and 400 children have a stroke in Australia each year.^{1,2} Stroke is among the top ten causes of death in children³ and the highest risk of childhood stroke is before one year of age.² More than half of childhood survivors of stroke will have a long-term neurological impairment.^{4,5} The causes of stroke in children are very different from those in adults. The most common risk factors for childhood stroke are arteriopathies (diseases affecting arteries) and congenital heart disease.^{6,7}

The effects of stroke are different for every child and are dependent on the area of the brain that was injured, and the degree of impairment caused. A child's brain is continuously developing and changing, and the effects of stroke may become more pronounced as a child grows, although in some instances may improve over time. Stroke can cause difficulties with sitting, standing, balancing and walking, and may also cause changes to the way the hand, arm and shoulder move. Changes in communication can also occur after a stroke, and a child may struggle to express themselves or to understand others. Stroke can impact a child's cognition, affecting how they think, learn, remember things and make decisions. Stroke can affect how well a child sees, as well as how they sense and perceive things. Other common post-stroke disabilities include swallowing difficulties, and 'hidden' impairments, such as fatigue, changes in personality, and regulation of behaviour and emotions.

The National Disability Insurance Scheme (NDIS) is one of the most significant social policy reforms in Australian history and is facilitating hundreds of thousands of Australians with disabilities, their carers, and families, to participate more fully in society and the economy. This includes thousands of Australian survivors of stroke. As of 30 September 2024, there were 9,822 survivors of stroke receiving support through the NDIS.⁸ Importantly, however, many other survivors of stroke with disabilities are either ineligible for the NDIS, or face challenges accessing, or fully participating in the scheme.⁹

Therefore, as the voice of stroke in Australia, Stroke Foundation welcomes the commitment of the Australian Government, and state and territory governments, to implement additional

supports to those delivered through the NDIS and mainstream services (Foundational Supports), to ensure children under 9 with developmental concern, delay and/or disability, their families and carers, do not fall between the cracks.

General Foundational Supports

Many childhood survivors of stroke have significant disability and complex needs, and for most types of Foundational Supports targeted at the stroke community, it is critical they are developed and delivered by organisations and individuals that have a strong understanding of stroke, stroke-related disability, and the impact this disability has on survivors, their family members and carers.

Foundational Supports should be delivered through a variety of channels where possible, including online, phone and in-person (groups or one-on-one), in order to accommodate the wide range of needs and preferences of those in the stroke community.

Outlined below are the types of information, advice, resource and capacity-building supports that childhood survivors of stroke, their families and carers need, some of which are delivered by Stroke Foundation, which as the leading national organisation focused on stroke prevention, treatment and recovery, is a trusted source of information and advice and deliverer of services.

Information, advice and resource supports

A child's stroke is a crisis for most families. Families have little understanding of stroke and disability when stroke occurs. This lack of awareness can make it difficult for families to make decisions and to support their child. In addition, there is often a lack of help and support available, and delays in diagnosis can be another issue faced by many families.

Stroke Foundation is committed to ensuring more Australians impacted by stroke can connect with and access trustworthy information, resources, and post-stroke support. Thousands of Australians benefit from Stroke Foundation's suite of resources and services which are designed to support survivors of stroke, their families and carers, and are provided thanks to the generous support of Stroke Foundation donors and partners. Our childhood stroke resources have been co-designed with Stroke Foundation's Childhood Stroke Lived Experience Advisory Group, to ensure they fit the needs of the community they serve.

Our Family's Stroke Journey is part of the *My Stroke Journey* suite of resources, and has everything parents need to know about stroke in babies, children and teenagers. This free resource includes stories from families, which provide insight into the road ahead, as well as a 'Strokesaurus' which explains medical terms.

The ***Childhood Stroke Project*** has delivered a wide variety of resources to support childhood survivors of stroke, their families and carers, including information booklets, brochures, posters, podcasts, webinars, videos and articles with tips and advice for parents and young people navigating life after childhood stroke. These co-designed resources are focused on ensuring families of children with stroke have what they need to manage their health and wellbeing, and achieve the best possible recovery for their child.

Stroke Foundation is partnering with the Murdoch Children's Research Institute on the ***Paediatric Acute Code Stroke (PACS) study***. Funded by the Medical Research Future Fund, this study is focused on transforming the care of children with stroke by dramatically decreasing time to diagnosis and increasing the number of children receiving reperfusion therapies. A critical component of this study is the presence of **Childhood Stroke Nurse Coordinators** at each of the major children's hospitals around Australia, who provide

comprehensive support to families, including school and community advocacy, and referrals to allied health practitioners and community agencies. Importantly, however, for families whose children experience stroke as babies and may not enter the hospital system due to delayed diagnosis, it is vital they have access to the same level of support in the community, for example through maternal and child health nurses or GPs.

EnableMe is Stroke Foundation's recovery website, which has been co-designed with survivors of stroke and carers. This provides videos, podcasts and fact sheets on a wide range of topics impacting daily life after stroke, a community forum to ask questions and share experiences, a tool to set and track personal goals for recovery, and an online helpdesk to ask questions of Stroke Foundation health professionals. In 2023, almost 70,000 survivors of stroke, their families, carers and health professionals, accessed 262,000 pages of information through *EnableMe*.

StrokeLine is a service that provides free expert information, advice, support and referral on stroke prevention, treatment and recovery to the general public and to survivors of stroke, their families, and carers. *StrokeLine* delivers services via telephone, email, social media and *EnableMe*, and aims to equip people to take action as required; however, if the individual contacting the service is vulnerable or at risk, *StrokeLine's* health professionals coordinate their care and follow-up as needed.

StrokeLine is a highly regarded, trusted service:

- In 2023, 89 percent of clients said they would recommend it to someone else. This was similar to 2022, indicating the service delivers a consistent and positive user experience.
- When advice was provided to clients about what they could do to resolve their issue, 77 percent acted on this advice.
- In 2023, there was a 34 percent increase in callers to *StrokeLine* asking for advice on signs of stroke before calling an ambulance.

We know from our own existing services' data and internal evaluation of the service, that **there is unfulfilled demand for StrokeLine**, with the current service unable to adequately meet the needs of specific groups within our community:

- *StrokeLine* provided information and support to almost 2,500 survivors of stroke, their families, and carers, and the public during 2023; however, this is only a small proportion of the number of Australians who experience a stroke for the first time each year, and are living with stroke in our community.
- In the last three years, there has been a significant increase in the number of complex calls into *StrokeLine*. This includes vulnerable survivors calling the service for advice and support, who are facing challenges with issues such as mental ill health, homelessness and social isolation, in addition to trying to manage the impact of their stroke. These calls are longer in duration and often require follow-up.

Importantly, Stroke Foundation can no longer deliver StrokeLine from donations alone, and we are calling on the Australian Government to invest in this highly valued service. This will ensure more survivors of stroke, their families and carers, regardless of where they live, are provided with the information, advice and referral supports they need in a timely manner.

Capacity-building supports

Families, in particular parents, play a critical role in a child's recovery after stroke; however, this support can come at a significant personal cost.

Findings from a survey of Australian survivors of stroke and their carers reported that of those carers who were working prior to taking on a carer role, 40 percent reported a moderate to extreme reduction in the amount of work they were able to perform.¹⁰ Almost half (47 percent) of the carers who participated in leisure activities prior to taking on a carer role reported a moderate to severe reduction in the number or type of leisure activities in which they were able to participate. A significant proportion of carers reported moderate to extreme changes in their relationships with family members (20 percent), and with other people outside the family such as friends (32 percent).¹⁰

Navigating life after childhood stroke, in particular the complex health and education systems, can be challenging for survivors and their families. Many of these challenges stem from a lack of understanding of brain injury in children, and how the injury impacts their abilities, behaviour and needs. This is particularly the case for children with 'hidden' disabilities such as fatigue.

Many childhood survivors of stroke face barriers to an inclusive education, where they are welcomed by their school and supported to reach their full potential. There are requirements for schools and teachers to make reasonable adjustments for students with disabilities; however, parents are still reporting that they are having to fight for accommodations such as the right of their child's therapist to come into school and work with them in the classroom.

Parents of childhood survivors of stroke have described taking their children to the GP after they have experienced seizures, or weakness on one side of their body, only to be dismissed as 'paranoid parents' and told to go home. This has resulted in their child missing out on critical early treatments. Therefore, there is a clear need for training and resources to improve GP understanding of stroke, particularly awareness of stroke in babies, children and young people.

As a consequence of all of these pressures, families and carers of survivors of stroke commonly experience a decline in their own physical and mental health and a reduced quality of life.¹¹⁻¹³

Parents of childhood survivors of stroke have explained the significant impact taking on a carer role has on their wellbeing. Many are juggling paid work and their caring responsibilities, because they have been told their child is not 'disabled enough' for them to qualify for a carers payment, and their caring role is part of their 'parental responsibility'. As unpaid carers, parents are often not eligible for the same benefits as professional or paid carers. For example, a professional carer who accompanies a child with a disability to a hospital appointment is able to claim the cost of hospital parking, while a parent who accompanies their own child to an appointment is unable to claim this. Parents have spoken about the toll all of these pressures take on relationships, and of the need for more publicly funded mental health supports for carers, including relationship counselling.

Capacity-building supports, including peer support and supports that help families better understand their children's rights, and develop the skills they need to advocate for them, can help in dealing with these challenges post-stroke.

Peer support

For many families and carers of childhood survivors of stroke, the emotional impact of stroke is often the hardest to deal with, and connecting with others affected by stroke can be an important step in helping to rebuild their life. Peer support groups for survivors of stroke and carers can offer therapeutic benefits including empowerment and inspiration, a sense of belonging, learning new ways to cope, feeling helpful, feeling secure, being able to express feelings, and a sense of increased agency and independence.¹⁴

There are stroke support groups across Australia, powered by survivors of stroke, and their families and carers, who want to see the benefits of peer support made available to as many people as possible. Some groups cater for everyone in a local area, while others are focused on particular age groups or interests. These groups provide a safe and supportive space where survivors of stroke, their families and carers are able to come together to share experiences, build friendships, learn more about stroke and self-care, try new things and build confidence, as they embark on their journey post-stroke.

In addition to facilitating social connection with peers, these groups also deliver a range of recreational activities, including mindfulness, meditation and cooking classes, art therapy, singing, and low-impact sports, as well as skill development activities and educational talks on topics of interest to their members.

[Little Stroke Warriors Australia](#), which is part of Stroke Foundation, is a support group for childhood survivors of stroke, their families and carers. This group provides survivors, families and carers with a supportive community to help steer them through the journey of stroke recovery, and raises awareness of childhood stroke, to make sure all children affected get the treatment and care they need, and that their families are well supported.

Australian and state and territory government investment is needed to ensure the benefits of peer support are available to as many Australian family members and carers of childhood survivors of stroke, as possible.

Self-advocacy and rights awareness

Unfortunately, many childhood survivors of stroke face a variety of attitudinal, physical, communication, social and policy barriers, which make it challenging for them to participate in everyday life, access the services they need, and succeed in education. There are many national and state and territory based organisations that are focused on supporting and advocating for the rights of people with disability, including survivors of stroke. Stroke Foundation advocates to Australian governments for policy and systems change improvements to better serve the needs of the stroke community. **We have also worked closely with advocacy organisations in the disability sector to successfully support individual survivors of stroke with a range of issues, including access to the NDIS.**

There are families and carers for whom the ability to articulate their child's needs and make informed decisions about the support necessary to meet those needs, is vitally important. A number of organisations in the disability sector provide workshops and other modes of training, which equip individuals with the skills and knowledge to effectively advocate for their child in a variety of contexts, such as the health or education systems.

Australian and state and territory government investment in disability organisations with a strong track record and expertise in self-advocacy training and mentoring is needed, to ensure the families of childhood survivors of stroke who want to develop the requisite skills and rights awareness to advocate for their children, are able to receive the training and support they need.

In summary, there are many national and state and territory-based organisations, including Stroke Foundation, that are delivering quality information, advice, resource and capacity building supports to meet the needs of children under 9 with developmental concern, delay and/or disability, families and carers. It is critical that the Australian and state and territory governments ensure that:

- these organisations have access to long-term funding, which will ensure they are able to deliver these supports in a sustainable way

- there are mechanisms in place to enable people with a lived experience of disability to participate in the design and implementation of these supports
- there is an effective process for disseminating and promoting information about these supports widely in the community, so that the greatest number of people are aware of, and are able to utilise and benefit from them.

Thank you for the opportunity to provide input into this consultation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Lisa Murphy', with a long horizontal flourish underneath.

Dr Lisa Murphy
Chief Executive Officer
Stroke Foundation

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