

INFO SHEET



This info sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/

NSW Paediatric Rehabilitation Services (NSW PRS) Family Engagement

What is family engagement

NSW has three specialist paediatric rehabilitation services known as the NSW Paediatric Rehabilitation Services (NSW PRS). These are located at:

- HNEkidsRehab, Hunter New England Kids Health, Newcastle
- Kids Rehab, The Children's Hospital at Westmead
- Rehab2Kids, Sydney Children's Hospital, Randwick

The NSW PRS are working together to provide the "right rehab care, with the right team, in the right place, at the right time". Involving families is an important way to understand how we can achieve this goal and improve our services. This information sheet is written to invite families to be partner with NSW PRS in decisions about planning the care and services we provide to children and young people.

Ways families can be involved in the NSW PRS

Family engagement can happen in many ways - from being informed of what is happening in the NSW PRS, to being part of one off or ongoing projects. Families can choose the time they can be involved, from a little to a lot. The list below are ideas about ways to be involved:

1. Being informed by:
 - getting email newsletters or updates of NSW PRS activities
 - reading fact sheets with general information about the NSW PRS

2. Being consulted by:
 - completing a survey about your experience of care by the NSW PRS
 - providing feedback on written consumer information to check if the content meets the needs of families
 - speaking with NSW PRS staff about your experience of care
3. Partnering with us by:
 - being part of NSW PRS working parties and workshops
 - being involved in quality improvement and research projects
4. Being empowered by:
 - being part of a NSW PRS committee that advises or creates ideas for the NSW PRS

Families have worked with the NSW PRS in a number of different projects to:

- improve the information we share with families
- develop consistent referral information
- how to make choices about telehealth

Future project work the NSW PRS would like to have families involved are:

- developing a NSW PRS website
- work with local services to provide shared care close to home
- forming an advisory group

Words from one of our family members involved in a NSW PRS working party

“Our son has been cared for by Rehab2Kids for nearly 11 years and being able to participate and contribute as a consumer in the model of care has had two fold benefits for myself and in fact our family, firstly an opportunity to give back in some way but almost more importantly to try and help in some small way so that everyone in NSW can have access to the same amazing care and kindness our family has had and continues to have from the many services we access”. Karen

Patient Reported Experience Measures (PREMS)

The NSW PRS teams are collecting information on the experience of families who attend an appointment with one of their teams. Feedback we receive will help us improve the services we provide. This information is being collected as an online survey. A link to the survey will be sent to you following your appointment and you can choose to complete the survey or not. At the end of the survey you can also choose to leave your details so we can get in contact with you.

Below is as an example from the first survey we trialed with families and the information they provide that helps us understand what we do well and where we can improve:

Feedback about the care they received

- 100% felt respected
- 95% felt definitely involved in decision making about their child’s care
- 95% rated their overall care very good
- 14% noted difficulties accessing the clinic (long walk, no accessible toilet)

Feedback about communication and information

- 100% felt staff explained things clearly
- 95% had enough information about Rehab provided prior to their appointment
- 80% were given enough information about their child’s care when they left
- 28% were provided enough information on how to comment or complain

How to get in contact with NSW PRS

If you wish to pass on a compliment or have any concerns about the care you receive please speak to any of the rehabilitation staff involved in your child’s/your care. We take your concerns seriously and are happy to discuss them with you, or direct you to the people who can best help answer your questions.

You can also get in contact with us via your local NSW PRS service:

HNEkidsRehab - Hunter New England Kids Health

- Phone: (02) 4925 7868
- HNELHD-SRC@health.nsw.gov.au

Kids Rehab - The Children’s Hospital at Westmead

- Phone: (02) 9845 0833
- Fax: (02) 9845 0685

Rehab2Kids - Sydney Children’s Hospital, Randwick

- Phone: (02) 9382 0178
- Fax: (02) 9382 0177