Working for a life free of pain.

Productivity Commission Submission - September 2010

ORGANISATION INFORMATION
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Mission and brief history of the organisation

Vision: Working for a life free of pain

Mission: Debra Australia provides ongoing support and information for individual, families, and professionals living and working with EB, ensuring all research and best practice treatments are investigated leading to improved quality of life for all.

History: Dystrophic Epidermolysis Bullosa Research Association Inc. (Debra Australia) is a non for profit organisation established in 2005. It is the only Epidermolysis Bullosa (EB) support group in Australia and is dedicated to funding essential support services to children and adults with EB, and give hope to people who desperately need it. There are approx. 1,000 people in Australia with EB ranging from mild to severe in condition. Debra is made up of volunteers and one part time employee. The organisation does not receive any government funding.

Debra has been successful in lobbying for a national EB Dressing Scheme which commenced in January 2010. This took 3 years of lobbying Local, State and Federal politicians. All EB families that meet defined eligibility criteria now get their dressings provided free of charge and delivered to their door step every month. Access to specific dressings has been in place in the United Kingdom and New Zealand for the last 10 to 20 years.

About Epidermolysis Bullosa

Epidermolysis Bullosa (EB) is a rare genetic skin condition where the skin blisters internally and externally. EB comes in 3 main types: Simplex, Dystrophic and Junctional and then there are many subtypes within these types. In the most severe forms, EB can be fatal at birth or lead to a lifelong of disfigurement and constant wound care requirements along with secondary complications.

Prevalence and Incidence of the Disability

There are approximately 1,000 people in Australia living with EB. Geographically located the majority of families are located on the eastern side of Australia. Debra support the funding of the only Australasian EB Registry which is managed by Professor Dedee Murrell at St George Hospital. This registry enables access to de-identified statistics of the EB population including location and type of EB amongst other information. Known Debra members living with severe EB would only fall into a category of approx 100 people. A recent publication giving some statistics from the Registry is attached.

Early education and support to EB families is essential to reduce isolation, hospital admission rates and the incidence of fatal cancer later on in life which is a common occurrence in people living with severe EB. Care services are also crucial in keeping the family unit intact, avoid breakdown in marriages and welfare payments.

Current Projects

A current Debra project is to implement a national Rapid Response EB Nurse Program to start addressing the inequity of EB care services across Australia. Currently there is one part time dedicated paediatric EB Nurse based in Sydney for the NSW region and a part-time general dermatology nurse in Victoria. All other areas in Australia do not have access to nurses with specialist EB knowledge. Funding has been secured for one year to allow the employment of two part-time Rapid Response EB Nurses who will travel to newly diagnosed babies and provide early education on dressings, support, medical care and nutrition to parents, schools, professionals and relevant community groups. This will improve community involvement, lead to improved patient wellbeing and equity of care on a national basis. Ideally Debra would like to evaluate this program over 3 years and has a fundraising schedule in place to enable the program to continue in years 2 and 3. During this time Debra will gather data to evaluate the program and hopes this evidence will convince the Government to improve EB services on a national basis.

Rationale for and Objectives of Long Term Disability Care and Support

Care requirements for EB patients are part time to full time depending on the severity of the condition. The majority of the carers are unpaid parents who are unable to continue in the work force. Many patients are heavily bandaged over large areas of their torso and limbs. Dressing changes can take up to 4 hours every 2 to 3 days on an ongoing basis. This has always been an issue with carer hours and hospital admissions.

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Over the years we have seen many families living with severe EB face several issues as they could not access respite care. Informal feedback from members has included the following issues:

- Lack of care services (including hours, trained staff and funding).
- Lack of training for local community services to have in place dedicated EB specific care staff to support EB families.
- Geographic issues if living outside of NSW, and in rural and remote locations.
- Lack of continuity of care and carers for those that are able to access care services.
- Families not having the time or skills to complete the necessary paperwork
- Unnecessary paperwork and revision required when care requirements are ongoing.

Other information will be made available when the EB Care Survey has been completed.

Key Design Elements of the New Scheme

To date the most obvious elements of a new scheme would include:

- Have in place funding for adequate number of care hours based on a needs basis.
- Streamlined system with one lot of paperwork on a national basis (user friendly).
- Funding National or State EB Nurses to educate the local community nurses to care for EB families (from paediatrics to adults).
- Work with peak bodies to maximise outcomes of the new scheme.
- Ability to access adequate respite care for stressed families.