



## A CLEARER PICTURE

Imagine being legally blind and without support. New research at Curtin is showing that this is the reality for more than 50 per cent of the blind population in Western Australia.

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**UNTIL** recently, little has been known about the prevalence of blindness in Western Australia. The Association for the Blind of WA holds the largest database of legally blind people in the state, and additional records are based on referrals from GPs, ophthalmologists and optometrists. However, these registers are voluntary and often incomplete: no one knows who might be 'falling through the cracks'.

The Epidemiology of Blinding Eye Disease (EBED) Study is providing the first comprehensive picture of people affected by blindness in WA, and how they are using the healthcare system. The study is being conducted by researchers from Curtin's Health Innovation Research Institute (CHIRI), consultant ophthalmologists and the Association for the Blind of WA, with funding provided by the Eye Surgery Foundation.

Julie Crewe, Research Fellow at CHIRI's Centre for Population Health Research, used a technique – 'capture and recapture' – first developed to estimate the number of birds in a flock, to determine the number of legally blind people in WA. Crewe's methodology

relied on comparing at least three lists of people, compiled from different sources. The most extensive list was supplied by the Association for the Blind of WA, with others compiled from hospital outpatient eye clinics and ophthalmologists' clinical appointments. These lists were compared to determine the amount of overlap of individuals between lists (recapture), and statistical analysis was then used to assess the degree of undercounting and estimate the size of the entire population.

"There were 1,771 legally blind individuals identified through our validated lists," explains Crewe, "but our statistical analysis has estimated that there are almost 3,400 legally blind people in WA.

"Only 2,244 people receive the blind pension, and the Association for the Blind of WA currently have 1,586 people registered for support. Despite the well-known benefits of rehabilitation, the results clearly indicate that more than half of the legally blind population are not accessing services.

"Surprisingly, this figure is higher than uptake rates reported nationally. But this

apparent mismatch between the need and uptake of services is clearly unacceptable for those living with blindness."

**DR MARGARET CROWLEY**, Chief Executive Officer of the Association for the Blind of WA, is enthusiastic about the study as a whole.

"The research helped us understand who is accessing our services, and has highlighted the need to look at our referral pathways. Outcomes are already changing our practice and methods of service provision," she says.

"It is an additional problem that many people are only referred to us once they become legally blind. We need to get them into the system earlier so they can access information and services, develop skills with assistive technologies, improve their social connectivity and maintain their mobility, while best using their remaining vision."

The EBED Study is now investigating the rates and duration of hospitalisation within the blind community. It paints a picture of a relatively invisible group who nonetheless rely much more heavily on acute-care medical services than sighted people, and further highlights the need for early intervention and rehabilitation.

Crewe sums it up: "Just knowing how many people are out there, and where the holes are, will assist in guiding the allocation of resources to help those living with blindness in our community." **C**