

BACKGROUND AND OBJECTIVE

Cerebral palsy (CP) registers gather data about populations of people with CP that can be analysed to inform service planning or provide sampling frames for research into treatments and causes. However, recent stricter privacy legislation has limited how data from individuals can be obtained, stored and used. The question now is can representative ascertainment, adequate numbers and data validity be achieved via a consent-based register?

METHODS

The Queensland Cerebral Palsy Register (QCPR) was established in 2005 as a register of people with CP who were born in, or have received care in Queensland, Australia.

Consent-based ascertainment involves 5 stages which is achieved with input from staff of the QCPR (1.5FTE) and clinical services: i) Identify participants; ii) Gain informed consent; iii) Obtain demographic data; iv) Verify diagnosis and classification; v) Enter data.

Reporting criteria for a birth year are: i) number of registrants meets/exceeds a prevalence of 1.5/1000 live births, and ii) reported fields contain data for at least 80% of participants.

Data was collected for 15 variables:

Demographics	CP Classification	Birth statistics	Associated Impairments
<ul style="list-style-type: none"> Gender Indigenous status 	<ul style="list-style-type: none"> Motor type Motor distribution Motor severity (GMFCS) 	<ul style="list-style-type: none"> Maternal age Gestational age Birth weight Plurality Neonatal care 	<ul style="list-style-type: none"> Vision Hearing Intellectual function Speech Epilepsy

RESULTS

Ascertainment: In 2012, after 7 years of data collection, the QCPR achieved consent-based ascertainment of 1980 individuals (with a 99.8% consent rate of those identified).

Minimum reporting prevalence was exceeded for a cohort of **10 birth years (1996–2005)**, which included 881 children, of whom 702 were born or received neonatal care in Queensland, equating to a prevalence of 1.6/1000 live births.

Data was reported for 15 variables (**Table 1**) and their interactions (**Figures 1-5**) (excluding post-neonatally acquired cases).

Population characteristics were consistent with data from registers with mandatory reporting.

CONCLUSION

- **Consent-based registers are viable for obtaining population-based ascertainment** if operational agreements exist with service providers in the geographical catchment.
- At minimum ascertainment, **population descriptions are similar to non-consent registers.**
- **Dedicated register staff are essential** for prospective recruitment, consent and follow up processes. Additional staff are required to retrospectively ascertain adults with CP.

Tab 1: POPULATION CHARACTERISTICS

Gender	Female	43.2%
	Male	56.8%
Motor type	Spasticity	87.1%
	Dyskinesia	5.5%
	Ataxia	3.9%
	Hypotonia	3.7%
GMFCS	I	31.8%
	II	24.1%
	III	15.5%
	IV	13.1%
	V	17.8%
Maternal age	<20 years	4.6%
	20-35years	76.9%
	>35years	18.5%
Gestational age	≤27w	15.0%
	28-36w	34.1%
	37-41w	46.8%
	≥42w	4.1%
Birth weight	<1500g	29.9%
	1500-2499g	19.5%
	2500-3499g	32.0%
	3500-4499g	18.3%
	≥4500g	0.3%
Plurality	Singleton	86.6%
	Plural	13.4%
Indigenous	Yes	6.7%
	No	93.3%
Neonatal care	NICU/SCU	66.3%
	Routine care	33.7%
Associated impairments	Visual	46.4%
	Hearing	13.1%
	Intellectual	52.3%
	Speech	59.5%
	Epilepsy	34.0%

Fig 1: VISION

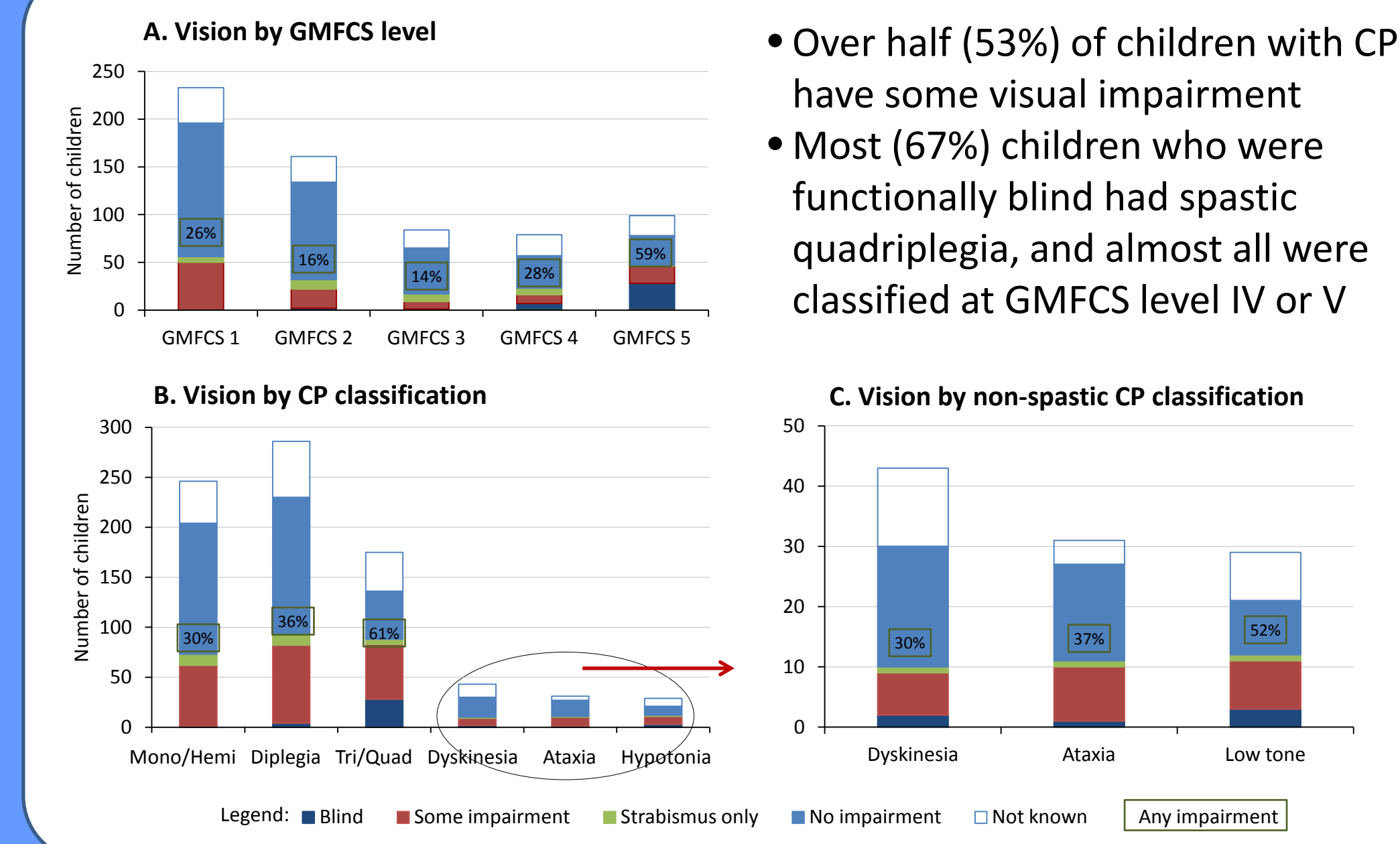


Fig 4: INTELLIGENCE

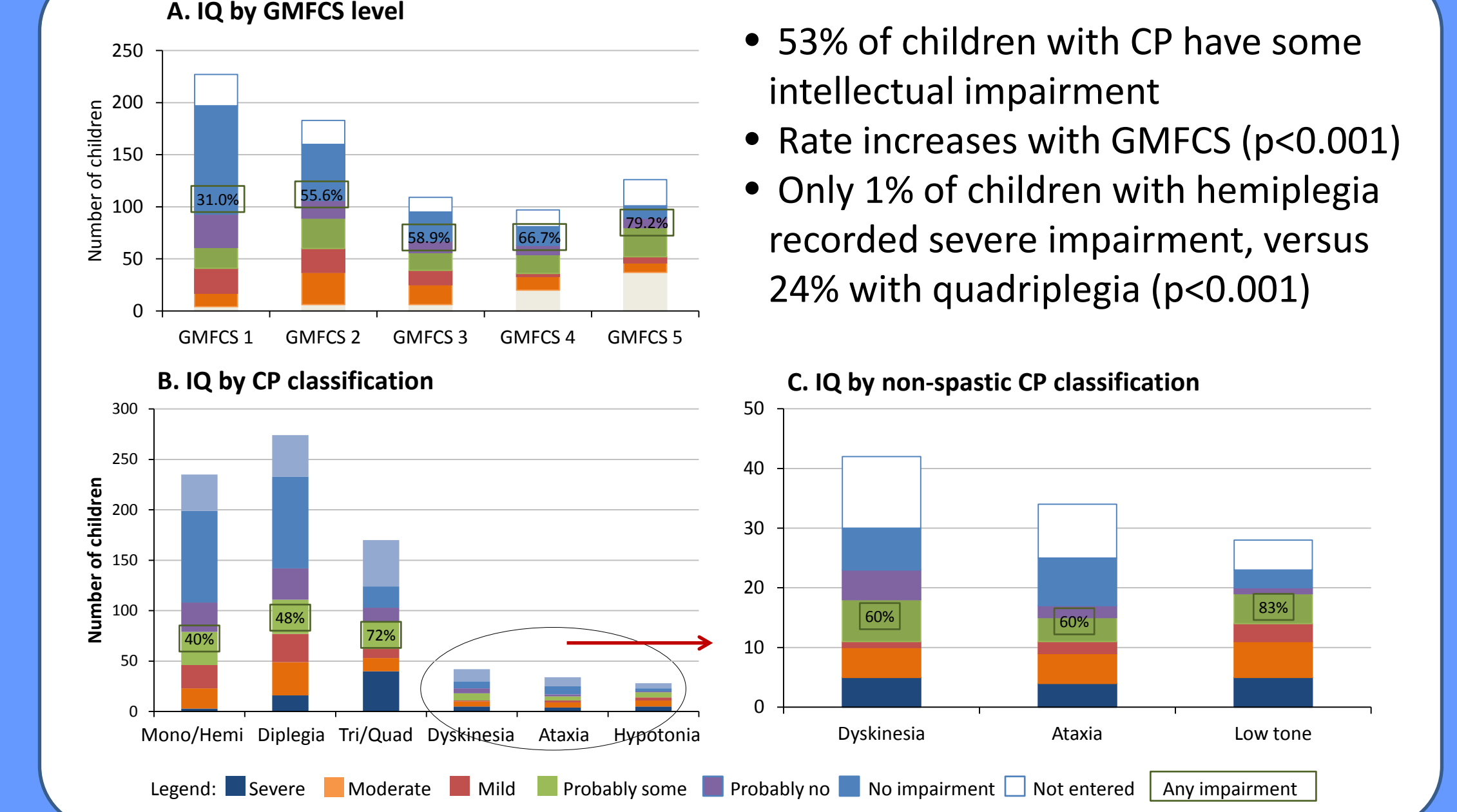


Fig 2: HEARING

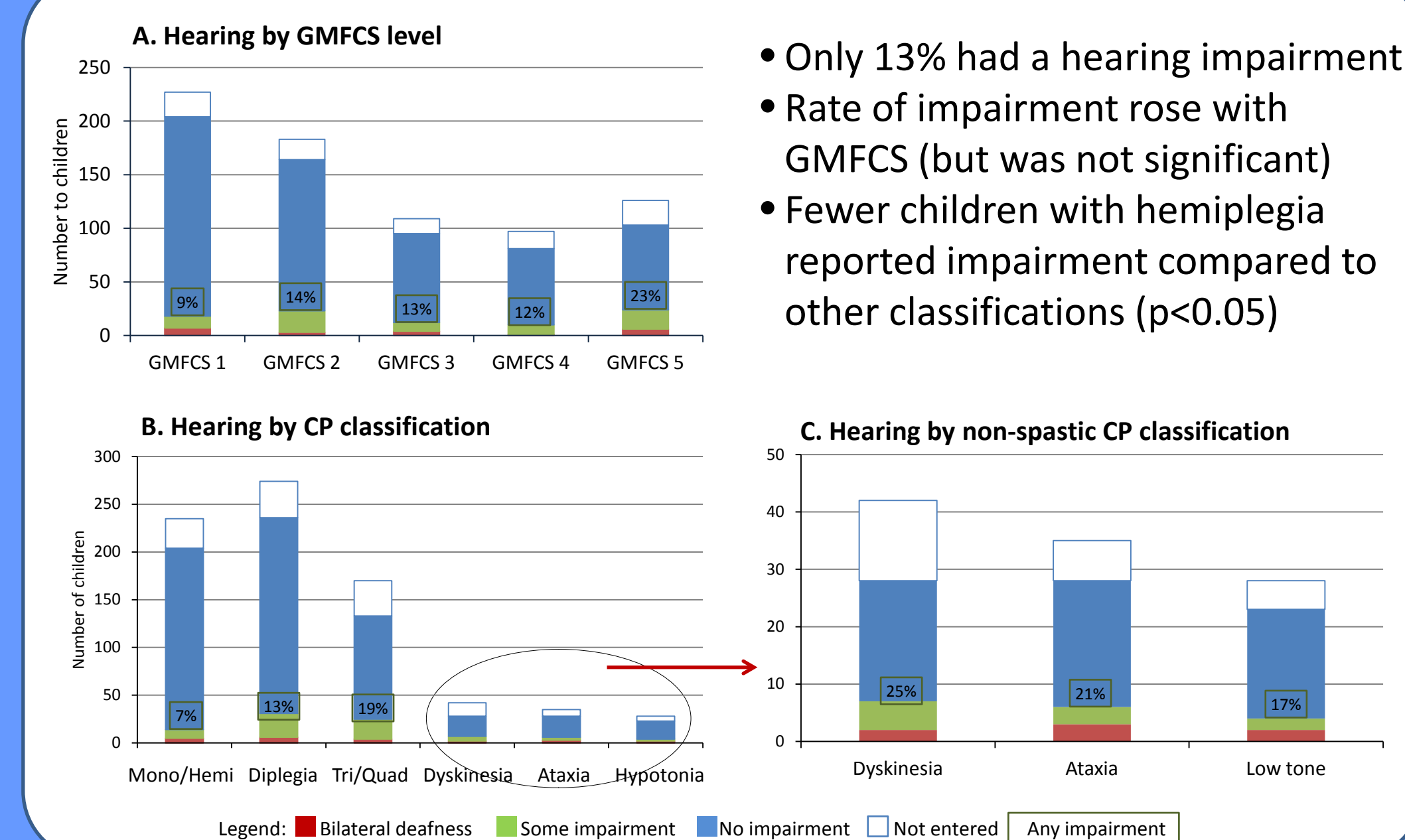


Fig 5: EPILEPSY

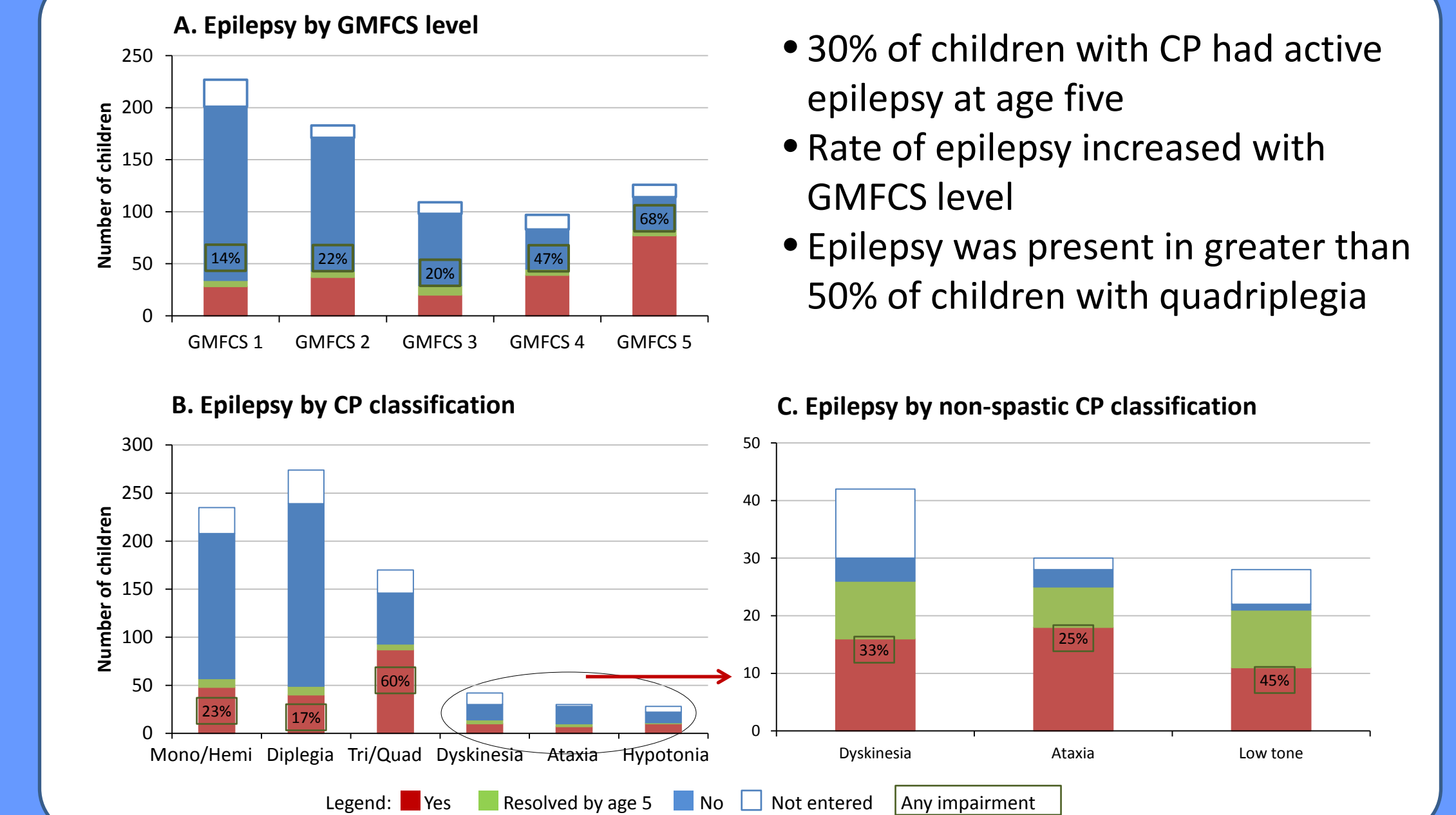


Fig 3: SPEECH

