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# INSPIRE

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## THE DISABILITY EDITION





# EPIC-CP PILOT TO BENEFIT ALL AUSTRALIAN CHILDREN LIVING WITH DISABILITIES



*Equitable Pathways and Integrated Care in Cerebral Palsy (EPIC-CP) is a global-first social prescribing intervention co-designed for and by people with cerebral palsy.*

**E**PIC-CP has the potential to help not only the cerebral palsy community, but also nearly 450,000 Australian children living with disabilities.

EPIC-CP is a pilot randomised controlled trial currently underway (2023-2024) at the NSW Paediatric Rehabilitation Services that explores the feasibility and acceptability of social prescribing to address unmet social needs. The trial engages families with a Community Linker and/or resource pack to access needed supports and services.

Supported by Luminesce Alliance, Sydney Children's Hospitals Foundation, and Cerebral Palsy Alliance Research Foundation, the EPIC-CP team co-designed the social prescribing program with young people with cerebral palsy, parents/carers, and service providers at the three Paediatric Rehabilitation Services of the New South Wales Children's Hospitals.

## ADDRESSING THE SOCIAL DETERMINANTS OF HEALTH

Cerebral palsy (CP) is a lifespan disability and the most common cause of physical disability in childhood.

Children with CP who experience socioeconomic disadvantage are more likely to have more severe health outcomes due to unmet social needs that impact health, i.e. food insecurity, poor housing, educational, and transport barriers.

Social prescribing addresses unmet needs by identifying these unmet social needs systematically and sensitively with a 'Community Linker' (a trained non-medical staff member) helping them access the health, social, and education services that they need.

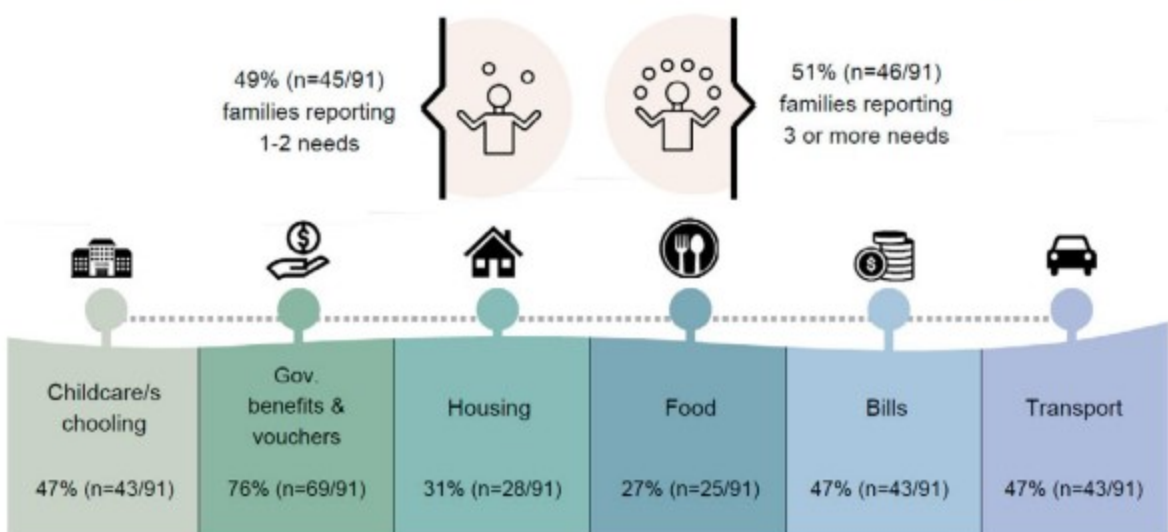
## CO-DESIGN AND EXPERIENCE OF PILOTING

Key to the success of this study was the involvement of families and clinicians as co-design research participants throughout. More than 200 participants contributed to the co-design research phase and the project was overseen by Research Advisors with lived experience of CP.

During co-design, many families of children with CP reported experiencing several unmet social needs affecting living conditions, health outcomes, participation, families' well-being, family functioning, and access to services.



## Of the n=91 families enrolled in our pilot trial



The complexity of systems made it difficult for families to address these challenges, which were made more difficult by the variation in the quality of services, unclear eligibility criteria of services, and administrative demands, (47%).

Feedback from co-design participants included:

*"I find the less advantaged you are, the more systems you need to negotiate. It actually snowballs, it becomes a bigger issue."*

*"Having an understanding, even knowing what's out there in the system is difficult for us and we work in the system."*

Rigorous co-design methods and continuing collaboration with stakeholders have ensured the creation of a programme that is responsive to the needs of its end-users and importantly, has standardised the identification and support for unmet social needs, with the intention of purposefully embedding the design in the current Australian health setting.

The pilot randomised controlled trial commenced in 2023 and will continue until late 2024. Currently underway, this pilot trial aims to support 120 families to access a Community Linker and/or resource pack.

To date, this pilot has demonstrated high feasibility of standardised universal identification of unmet social needs, with approximately two-in-three families reporting 1 or more unmet social need. The most common needs are government benefits and vouchers (76%) followed by transport, bills and childcare/schooling

### NEXT STEPS

Further to EPIC-CP, Luminesce Alliance funding has supported lead researchers Professor Sue Woolfenden and Dr Katarina Ostojic to partner with other clinical groups passionate about implementing social prescribing initiatives in their local settings. This includes collaborations with teams from community paediatrics, brain injury services, and paediatric cancer services.

This collaborative partnership between funders, people with lived experience of CP, researchers, and clinicians was leveraged to successfully receive a \$1.46 million Medical Research Futures Fund grant for the next phase of research (2023 MRFF Clinician Researchers Initiative). The MRFF project will evaluate the effectiveness of the social prescribing program for children with neurodevelopmental disabilities in NSW, with robust implementation and economic evaluations.

### CONCLUSION

The outcomes and further funding of the EPIC-PC program represent a significant step forward in improving healthcare policy to support disadvantaged children and young people. The EPIC-CP pilot demonstrates how social prescribing can help not only the cerebral palsy community but also nearly 450,000 Australian children living with disabilities.

**Authors:** Professor Sue Woolfenden is the Director of Community Paediatrics at Sydney Local Health District and Professor of Community Paediatrics at The University Sydney. She has 30 years of extensive clinical expertise in working with children from priority populations. Sue has led research that investigates the impact of inequitable health service provision on child health outcomes in the early years of childhood in Australia and globally.

**Dr Katarina Ostojic** is a Research Fellow at The University of Sydney and Adjunct Associate Lecturer at The University of New South Wales. She is a mixed-methods researcher with a strong focus on addressing inequities in health care and supporting young people and their families to improve their mental health, psychosocial functioning, and participation.