THE CO-PRODUCTION JOURNEY: DESIGNING THE SERVICE FOR INJURED CHILDREN AND THEIR FAMILY

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Aim: To improve insight into patient and family experience of paediatric major trauma from prevention to rehabilitation using co-production.

Introduction:

- Morbidity from paediatric trauma has profound and long-lasting effects on the family and wider community.
- A gap exists between the current service and that which best serves patients.
- Improvement requires a mutual understanding of the experience and needs of the service user.
- This can be achieved through empowering the patient and family to engage as equal partners with clinicians to design (co-produce) a service that will work for them.
- Co-production has significant benefits in improving patient outcome.

Assets: Transforming the perception of people from passive recipients to equal partners.

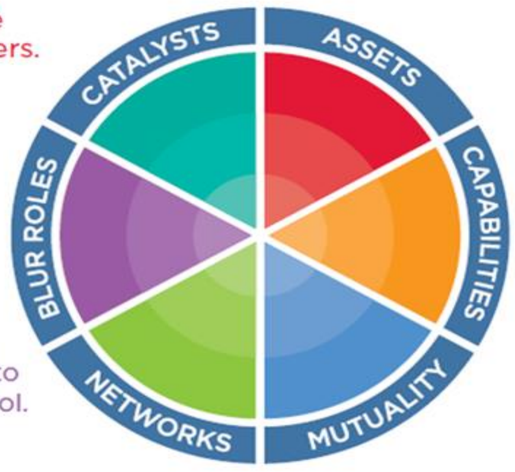
Capabilities: Building on what people can do and supporting them to put this to work.

Mutuality: Reciprocal relationships with mutual responsibilities and expectations.

Networks: Engaging a range of networks, inside and outside 'services' including peer support, to transfer knowledge.

Blur roles: Removing tightly defined boundaries between professionals and recipients to enable shared responsibility and control.

Catalysts: Shifting from 'delivering' services to supporting things to happen and catalysing other action.



People Powered Health Coproduction Catalogue, NESTA 2012

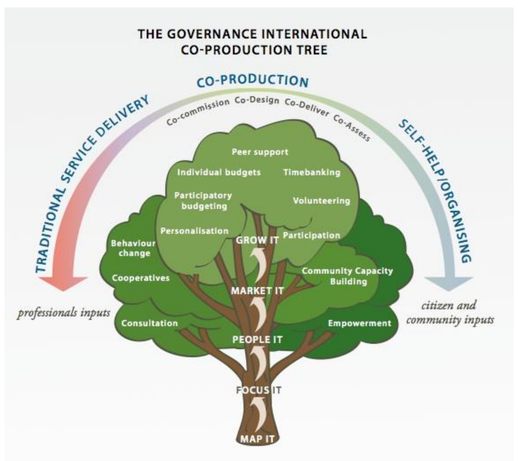
Methods:

Researcher identified an index case and spent time in the home environment to collect qualitative data of their experience. Co-production methodologies were used to facilitate identification of key issues and strategies for improvement.

Results:

Discussion identified multiple issues encompassing gaps in the community for injury prevention through to the daily challenges faced in rehabilitation
The highlighted issues are those deemed important to the family and suggested strategies for improvement developed together with the researchers.

	Problems	Strategies
Injury Prevention	• Potential behavioral problems unidentified • Lack of community based activities, youth clubs etc.	• Identification and minimisation of at risk behaviors (heath care, school) • Engage community members and leaders to establish safe activities
Golden Hour	• Delay in injury identification pre-hospital. • ED family room "horrendous" - lack of privacy, cold, blank	• Review of triage undergoing with LAS. • Review design and location of family room: furnish, away from main corridors
Active Treatment	• Lack of support following initial breaking bad news (BBN). • PICU - interview room for BBN opposite family room - lack of privacy, connotation of bad experiences. • Ward - focus on patient, little support for families. • Dignity - uncomfortable for teenage boy to be nursed by young female nurses. • Problem: Rapid staff turnover - complex injuries and challenging behaviors that few were familiar with. • Felt excluded from adolescent events as not set up to support those with complex injury and behavior.	• Dedicated neurology clinical nurse specialist (CNS with interest in traumatic brain injury) now on staff. Allocate a staff member to act as family liaison early on. • Review design and location for family room away from main corridors. • Improve staff awareness of family needs in severely injured children. • Considered staff allocation where possible. Aim to provide continuity of staff. Long term need for encouragement of more males to enter nursing and allied health care professional roles. • Plan activities suitable to all.
Rehabilitation	• Gap in service for adolescent inpatient rehabilitation. Long waiting list. • Limited availability for community rehabilitation. Long distance to travel for specialist rehab services. • Access to respite care.	• Development of dedicated adolescent rehabilitation service. • Engage and educate local therapists to provide care in the community. • Engage local community to improve availability of services
Social	• Significant financial burden on family - long inpatient stay - travel, meals, loss of earnings and employment. Lack of awareness of available benefits.	• CNS role. Development of an information pack with these details and points of contact for help and support to be created
Lifelong	• What will happen to my child when I am gone?	• Engage co-production principals to develop services to allow injured children to thrive and meet their potential



Conclusions:

- Empowering service users to engage in service design promotes provision of effective patient centered care.
- Co-production has the potential to improve outcomes for injured children by closing the gap between the current service and a service designed around patient needs.
- Co-production offers a novel opportunity to design a service that improves outcomes, satisfaction and quality of care.

References: Bovaird T, Loeffler E. (2013). *We're all in this together: harnessing user and community co-production of public outcomes*. University of Birmingham, Institute of Local Government Studies and Third Sector Research Centre.

Loeffler et al 2013, *Co-Production of Health and Wellbeing in Scotland*