Campaign to fight feeding tube stigma

1. Summary of impact

Spend time with new parents, or in a baby health clinic or maternity ward, and the 'breast v bottle' debate is still bubbling away. But there is a third way to feed that's very rarely talked about: by tube.

"As a parent with a child with a feeding difficulty, every time you only hear 'breast and bottle', your child is left out, your child is excluded. They're made invisible," explains Nick Hopwood, Associate Professor at UTS's School of International Studies and Education.

Nick is working with clinicians across several states, families and researchers at UTS and Western Sydney University to tackle the stigma.

As part of the Social Impact Grant funded project, parents participated in workshops at the Design Innovation Research Centre at UTS to lay the groundwork for a public awareness campaign on the misunderstood medical intervention.

Based on ideas developed in the workshops, students from UTS's volunteer program Shopfront were able to create videos, branding and key messaging that may be developed further by the team.

2. The problem

The families of babies and infants with feeding tubes face stigma in everyday life, with most people unaware of why tubes are used and fearful as a result.

“Friends might stop coming on play dates because they worry that their kids are going to do something that’s going to hurt the child or pull the tube out, or they’re just too awkward to talk about it. They might even decide to not invite them to birthday parties because they’re worried about the food, and that the child is going to miss out,” explains Nick.

These well-meaning but unhelpful attitudes aren’t helped by the media, film makers and charity advertising, which tends to use images of children with feeding tubes as a shorthand for serious illness.

3. Beneficiaries

The families of children with feeding tubes will benefit from the public awareness campaign to reduce stigma around feeding tubes that will ultimately come out of the project.

4. Approach to impact

Parents were empowered by a co-design process the team undertook with Design Innovation Research Centre (DIRC). From the beginning, they were integral to the project, says Nick.

The co-design workshops involved parents in developing the design and communications thinking behind a public awareness campaign. Together, parents and researchers determined:

- What the public awareness campaign messages should be
- What the principles behind it should be
- What should change in terms of current messaging
- Who it should target.

Volunteer students were then able to use the workshops as the basis for three short animations, branding and a tag line: “tubes fill stomachs but sharing meals fills hearts.”

5. What has changed as a result of this work?

5.1 The outcomes

Student volunteers have created three short animations to help parents communicate about their child's tube with friends and family. The videos will be used as a basis for a campaign to reduce stigma and raise awareness in the wider community.

5.2 Impact

The main aim of the project is to get information out into the community about tube feeding to reduce stigma, but it has also empowered some of those with the most to benefit from changing community attitudes – parents.

The workshops held at DIRC were an opportunity for parents of children with feeding tubes to talk openly about difficult topics without fear of judgement. Ultimately, the team hopes wider impacts will be more awareness in the early childhood community about feeding tubes.

"Ideally, we'd like to see the positive images and stories we've created on every nappy box so that every family knows more about the issue."

6. What has helped you accomplish this work?

The Centre for Social Justice & inclusion not only helped fund the project through a Social Impact Grant, it also connected the project team with experts in co-design at DIRC and UTS's student volunteer program, Shopfront.

7. Challenges

Despite receiving $5000 in Social Impact Grant funding, money has been tight. This has inspired the team to get fundraising to expand the public awareness campaign. You can donate by visiting the Childfeeding.org website.