

Translating Evidence in the disability sector: E-Peer-support to disseminate consumer voices

Annick Janson, Associate, Centre for Applied Cross-cultural Research, Victoria University of Wellington & Ecosynergy Group, Hamilton, New Zealand.
Barry Davies, General Manager, Te Whanau Kotahi, Tauranga, New Zealand

Introduction: Finding the voice

The Consumer Storytelling project addressed knowledge gaps (MacLellan-Wright et al., 2007) surrounding user experiences (Coney, 2004) in the Disability sector: "What difference do services make to consumers?" and "How do consumers navigate services through milestone family events to achieve a 'good life' initiative (New Zealand Ministry of Health, 2012)?"

A 'Lived Experience - Peer Knowledge-Sharing' model was developed as a proof of concept to:

- Enable a diverse group of consumers to recount their experiences by putting in place effective and targeted mechanisms to capture stories and
- Test a participative story selection and evaluation methodology mechanism to represent and honour the diversity of consumer voices.

Methods: Answering the call to action

Thirty telephone interviews, 3 workshops, 10 individual video recording sessions and 10 individual feedback sessions were carried out. Parents trained in storytelling methodologies (Janson et al, 2008) to describe empowering experiences as they overcame multiple challenges in advocating for inclusion (Kendrick and Sullivan, 2009). Participants implemented the Most Significant Change participatory methodology (Dart and Davies, 2003) to collate their narratives.

Results

Findings inform service delivery and policy development in the Health & Disability sector – where quantitative measures are traditionally preferred. Parents shared stories about advocating for and creating sustainable change for their children and families. As part of their leadership development path, they decided to take action to reach key decision makers, service planners and service providers in the sector – where parents' voices needed to be heard. In the process they built sustainable leadership, joining efforts to translate their knowledge to other families, practitioners and policy makers. Participants developed:

Self leadership

Bank on your child's most important advocate - you!
Take care of yourself and your core relationships
Find out unique information
Identify your fears [what stops you from taking action?]
Appreciate the gifts and talents of your child

Peer leadership

In taking control, you inspire others to make changes
Discuss choices and options with others
Identify the insights you get from others

Community leadership

Your actions have ripple effect on the whole sector
Yes, you can sometimes know more than the experts! ... and from that position, you can contribute to the sector

Family leadership

Your decisions stir your family's direction
Think about work/family balance

Audience

25,890

viewers on the E-Peer Support channel (*)
(*) www.youtube.com/ecosynergygroup

1,364

E-Learning registered users and staff working alongside at-risk youth

Specialised Materials **155**

video clips Disability E-Peer Support

1,730

views sharing resources
(Individualising disability support from In Control, UK)

Engagement

1,974 Average views/quarter

1,187 **47** Peak views/day

individual views last quarter E-Peer Support for parents. Average watch via mobile may be 5 times longer (possibly watched during 'down time')



Usability testing target audience comments

"Sometimes it is only at 11pm when kids are asleep that I have the mental energy to put into myself. I want to learn - in my own time"

"If I had had access to such stories when my child was first diagnosed, our lives would have been different. When you realise your child has a significant issue - whether it is at birth or later on - your whole world is turned upside down and you need a massive amount of (the right) support to get through"

"We had no idea other people felt the same as us. Doctors say nothing because of confidentiality issues and this reinforces the despair and isolation you find yourself in. Some peer groups I attended or individual conversations aggravated the situation as I found myself amongst people who were more into complaining than building strength"

"What I liked about this material is the power building angle they take - I get an idea, a different perspective or a new thought. I can browse the stories via the written material or listen/view a story at the time that best suit me. I want to contribute to developing this resource further so that in the future families can learn about the growing list of issues that we all face as life goes on - and come out stronger for it!"

Knowledge Translation

Participants reviewed 90 min. of video material collected and selected themes to embed in a Significant Story Trailer to represent their experiences (<http://tinyurl.com/E-Peer-Support>). Most participants preferred the flexibility and sustainability over time that sharing knowledge via the E-peer-support platform affords – as opposed to attending face-to-face workshops. The group planned a dissemination pathway, including the use and monitoring of Social Media, to spread their message deeper into targeted audiences.



Example 1:

Example 1: Interactive introduction with on-screen buttons linking to more in-depth interview materials during trailer playing time – tailoring the impact of the material to its audience.

Example 2:

Flexible access online and via mobile devices and tablets, complemented by a written 'Parents' Guide' (Janson, 2013)

Example 3:

Dissemination via targeted audience social media / personal networks.

2,578 ten days later, travelling from page to page into other parents' social networks and highly relevant target population.

Discussion

Do we need to transcend face-to-face delivery formats to reach our audiences? And if so, what channels should be used? Traffic data shows that our audience has already moved on from these traditional approaches, searching cyberspace to learn - overcoming distance to learn from peers, sometimes very close to real time, supporting Van Eden's recommendations (2013) to share stories and build peer support for the sector. Moreover, rich media may be fertile ground for novel cultural engagement for diverse cultures using oral storytelling traditions. Finally, our audiences may be using 'down time' or travelling time away from offices, homes and computers to access these via phones and tablets. Further exploration is needed to understand how to build on the added value of mobile devices to E-Peer-Support programmes.



Journey of a facebook post:

A story posted on Facebook reached 11 in an hour

34 by the evening, 75 direct reach

Contact

Dr. Annick Janson
+64 27 288 1949
annick.janson@egl.ac.nz
www.fasttrackinclusiontrust.blogspot.com
www.victoria.ac.nz/cacr/about-us/people/associates/annick-janson

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