

Building capacity in families and communities
to maximise communication with children who
have multiple and severe disabilities: A research
agenda

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Background

- Complex needs of children with MSD pose challenges to social inclusion and full participation in everyday life situations
- Typically minimal or no speech – challenging for families, friends and others in community to interact with them
- We know from studies involving teachers and speech pathologists that factors influencing communication opportunities and participation of these children at school are multiple and complex, eg.

Background

- Other environments are important for children with MSD – home and community – but we don't know how much communication is occurring there
- Central role of families, friends and others in the community in facilitating communication opportunities for children with MSD – but we know little about their experiences and support needs

Background

- Challenges and opportunities of NDIS – greater say for families; new skills and knowledge needed
- Deregulation of the disability sector in NSW
- Need better understand of barriers faced by and support needs of children with MSD, their families and communities
- Need to build a robust evidence base for practices that build capacity
- Inequities in access to support from specialist services for children with MSD and their families living outside metropolitan areas in NSW

Aims of the study

1. To identify supports and obstacles to communication for children with MSD – from the perspectives of the children themselves, their families, friends and others
2. To trial an approach to empowering families and communities to enhance communication with children with MSD
3. To develop an evidence-based model that can be taken to other regional, rural and remote areas

Methodology: Overview

Pilot study

Qualitative –
interviews, focus
groups, behavioural
observation

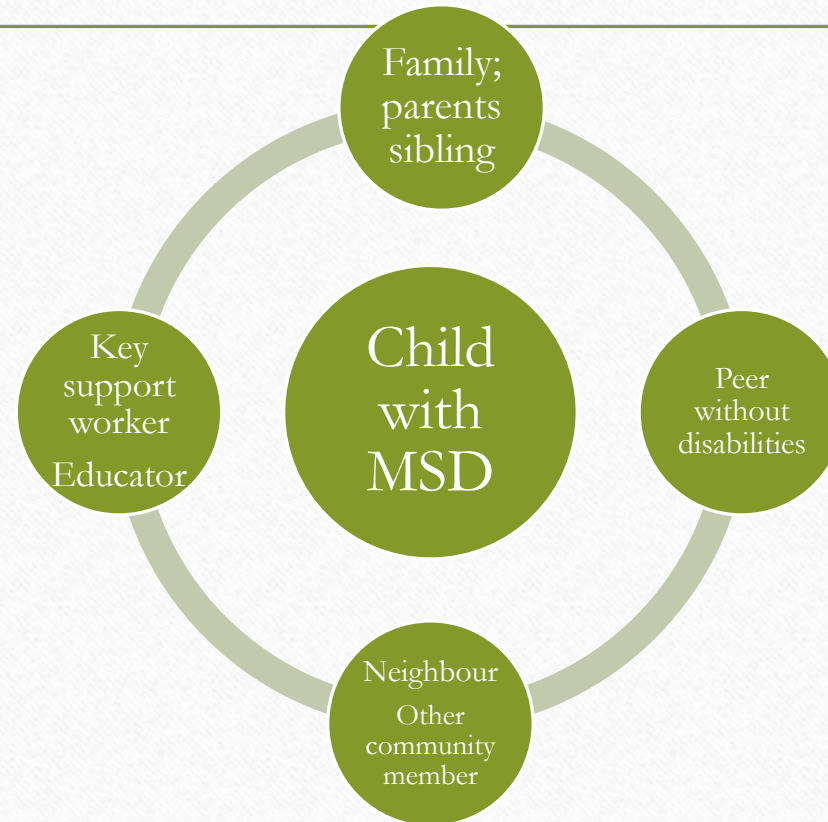
Participatory
action research

3 Phases

1. Information gathering
2. Interventions
3. Evaluation

Methodology: Participants

5 case study groups, each comprising:



Methodology: Phase 1

- **Purposes:**

1. Find out how much communication occurs between children with MSD and family, friends and others
2. Identify facilitators and barriers to communication from perspectives of children with MSD, their families, friends and others

- **Methods:**

1. **Observations** of children with MSD communicating with others
2. **Individual interviews** with each participant, incl. children with MSD.

Methodology: Phase 2

- **Purpose:** Explore potential for families, friends and others to plan and implement interventions to improve communication with children with MSD.
- **Methods:**
 1. **Case study focus groups** – share and discuss themes from interviews; develop action plans
 2. **Implementation** – of action plans by each case study group
 3. **Observations** - continued

Methodology: Phase 3

- **Purpose:** Evaluate outcomes of implementing action plans
- **Methods:**
 1. **Case study focus groups** – discuss/ review progress of the action plan; assess effectiveness of implemented actions
 2. **Observations** – collecting maintenance data

Outcomes and Implications

- Information about key factors that come together to result in positive, or otherwise communication outcomes for children with MSD IN REAL LIFE
- Better understanding about how important people in the child's life might work together to make changes that enhance the child's participation/inclusion
- To empower families and equip practitioners to negotiate new environment, eg helping families to identify how a speech pathologist can support them to 'live their lives'

Future Directions

- Based on findings of the pilot, start putting together a blueprint/framework for support that can be further trialled with families and communities who have children with disabilities in regional, rural and remote areas
- Broaden the focus to include children with disabilities, their families and communities
- Participatory action research partnerships

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