MUSCULAR DYSTROPHY NSW
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

Theory of Change

THE NEED

PROBLEM

Approximately 13,000 people in NSW live with muscular dystrophy – an umbrella term for hundreds of rare, complex genetic neuromuscular conditions (NMCs).

Across the lifespan, people with NMCs and their families often face the journey without clear information, emotional support or connection to others who understand. Too often, they're left to navigate fragmented systems alone, where services exist but are difficult to find or access. These challenges intensify during times of transition.

The result? Too many people without the tools, networks and guidance to confidently shape their own path.

PEOPLE

Children, young people and adults living with neuromuscular conditions in NSW, along with their families and carers.

REASON

Because every person needs a voice, choice and community.

THE WORK

PARTNERS

- Neuromuscular clinics and healthcare providers
- Universities and research institutions
- Systemic advocacy organisations
- Other MD organisations

INTERVENTIONS

New Diagnosis Companion
Timely, tailored support for children and families at the point of diagnosis.

Peer Connect
Opportunities to connect with others who share lived experience.

Camps and Retreats
Programs to build independence and confidence in accessible environments.

NDIS Support Coordination
Individualised support to help people understand and implement their NDIS plan.

Advocacy
Engagement with policymakers and systemic advocacy organisations.

Information and Referral
Connection with information, resources and services.

INPUTS

- Trained staff and volunteers
- Active peer and referral networks
- NDIS expertise and support
- Philanthropic and government funding
- Accessible venues & accommodation
- Technology and infrastructure

ASSUMPTIONS

- MDNSW is adequately funded and resourced.
- Clients have sufficient NDIS funding to access camps and retreats.
- Community members have the time and support to attend MDNSW events.
- Qualified staff and volunteers are available to facilitate programs.
- Partners refer clients to MDNSW.

BIG IDEA

Your neuromuscular support community – at every life stage

MISSION

Supporting people living with neuromuscular conditions and their families through information, connection and advocacy.

THE RESULTS

SHORT-TERM OUTCOME

Stronger connections, inclusive networks and meaningful engagement for people living with neuromuscular conditions.

OUTPUTS

- # of camp and retreat participants
- # active peer connect participants
- % of participants reporting improved self-confidence
- % of participants that gained condition-specific knowledge
- % of participants that developed peer connections
- % of participants that developed improved decision making skills
- % of participants reporting increased skills
- % of participants reporting improved self-advocacy skills
- Retention of participants year on year
- # of Sydney Metro vs regional NSW participants

SUSTAINABILITY PATHWAYS

65+ years embedded in the NSW neuromuscular community ensures our support is lasting, trusted and adaptable.

LONG-TERM OUTCOMES

- People gain confidence, knowledge and skills to make informed decisions and advocate for themselves.
- People build meaningful peer connections programs.
- Participation develops practical skills and self-confidence.
- Ongoing participation strengthens engagement and retention, sustaining a connected neuromuscular community across NSW.

BIG HAIRY AUDACIOUS GOAL

A thriving neuromuscular support community spans every region of NSW – led by lived experience and built on connection.

VISION

Every person living with a neuromuscular condition and their families experience choice, confidence and community.