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# **How do we empower people with disability to speak up?**

**Rights Project for People with Disability**

# NSW Ombudsman responsibilities in relation to disability service providers

- handling and investigating complaints and reviewing complaint-handling systems
  - inquiring into major issues affecting people with a disability and service providers
  - reviewing the deaths of people with a disability living in residential services
  - monitoring, reviewing and assisting in setting standards for the delivery of disability services
  - coordinating the Official Community Visitors scheme
  - providing information, education and training about complaint-handling
  - oversight of service provider responses to alleged incidents of abuse and neglect involving people with disability who live in supported group accommodation - Disability Reportable Incidents scheme
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## Project Aim – Rights Project for PWD

Develop a practical and lasting framework that enables people with disability and their supporters to better understand and exercise their rights.

Assisting people with disability to:

- Identify when things are not ok and they need help
  - Speak up to make complaints, report abuse, neglect or ill treatment
  - Make decisions, and
  - Where to get help.
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## Our three main focus areas

Build the capacity of people with disability and their supporters to understand and exercise their rights as NSW moves towards the NDIS:

- 1. Empowering people with disability to understand and exercise their rights*
  - 2. Promoting accessible complaint systems and practices amongst govt. agencies and disability service providers*
  - 3. Strengthening systems to prevent, identify and respond to abuse, neglect and/or exploitation of PWD*
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## Empowering people with disability to understand and exercise their rights

- Speak up! – Rights based training for people with intellectual disability
  - *My right to be heard* video
  - Expert Forums – people with complex needs and hard to reach groups, people with intellectual disability, people with psychosocial disability
  - Joint Advisory Committee (JAC)
  - Observations paper (Speak up! workshops)
  - Final report on the project – Q&SF
  - Zero Tolerance and Staying Safe Training
  - Development and distribution of relevant materials
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# Promoting accessible complaint handling systems and practices

Working with government agencies and other service providers to improve the accessibility of their complaint systems for PWD by:

- *My right to be heard video* on person-centred complaint handling
  - Tips Sheet to promote accessible complaints handling
  - NDIS training for consumers, front line staff and managers
  - Complaint handling training for disability frontline workers
  - Training and organisational support on implementing a quality disability complaints system
  - Training on disability awareness
  - Promoting a consistent approach amongst oversight/regulatory bodies
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## Strengthening systems to prevent, identify and respond to abuse, neglect and/or exploitation

- Ongoing sector engagement about quality systems and strategies for preventing, handling and responding to abuse and neglect of people with disability – Disability Reportable Incidents scheme, Best Practice Working Group, Provider Roundtables
  - Forum on *Addressing the abuse, neglect and exploitation of people with disability*
  - Training for service providers on responding to serious incidents and conducting investigations
  - Guidance resources on interviewing a person with a cognitive impairment
  - Early responses to serious disability incidents
    - Joint Protocol to reduce the contact of people with disability in supported accommodation with the criminal justice system
    - The Initial and Early Response to abuse and neglect in disability services - resource guides & flow chart
  - *Issues in recognising, reporting and responding to client to client incidents under the NSW Ombudsman Disability Reportable Incidents Scheme* – file review and paper by Associate Professor Leanne Dowse, Chair in Intellectual Disability Behaviour Support, UNSW
  - Fact sheets regarding NSW Ombudsman oversight of specific types of incidents
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## Reporting incidents of abuse and neglect

- NSW Ombudsman Disability Reportable Incidents scheme – since Dec 2014, our office has received 1481 notifications of incidents of alleged physical or sexual abuse, AVO breaches, neglect, ill-treatment or unexplained serious injuries of people with disability
  - There will be a national mechanism for reporting incidents under the NDIS – the NDIS complaints commissioner will monitor and investigate serious incidents, receive and respond to complaints about NDIS funded supports, and breaches of the NDIS code of conduct
  - Ongoing capacity building to encourage and enable people with disability to speak up under the NDIS will be vital.
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# What stands in the way of people with disability speaking up?

- *“In relation to people with intellectual disability, Fitzsimons reminds us of the personal barriers which lead to a vulnerability to abuse “[these] include learned helplessness, low self-esteem, self-blame, denial, sense of responsibility to others, fear of retaliation, fear of the unknown, lack of skills and knowledge, poverty. People with a disability, particularly intellectual disability, have learned to comply with the directions of those they believe are in positions of authority. As a result they are less likely to resist or report abuse”. Many participants in the scheme will struggle to recognise and report on poor quality service as well as matters of abuse or behaviour which harms them...”*
  - Endeavour Foundation submission to the National Quality and Safeguarding Framework.
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## What skills are needed?

Some of the broader skills that stakeholders suggested should be fostered among NDIS participants include:

- understanding and asserting rights and responsibilities
  - informed decision-making
  - communication
  - managing budgets
  - building healthy relationships
  - recognising good and bad quality supports
  - recognising and responding to violence, abuse or neglect, and
  - making a complaint or suggestion.
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## Extra supports

- Many participants may only require access to information to exercise choice and control, but many will need extra support to navigate the NDIS from:
    - a local area coordinator,
    - support coordinator or
    - other knowledgeable person.
  - In particular, stakeholders identified that people with intellectual and cognitive disability and people with complex communication needs can face much greater barriers to exercising choice and control and will need access to decision-making and other supports.
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## A word from VALID – [valid.org.au](http://valid.org.au)

*“For many people with intellectual disability, the lack of self-advocacy skills limits their development as confident, effective individuals...*

*(All of us) are constantly refining our skills, practising our strategies, trying to acquire increased control over our own lives, and trying to achieve the things we want from life.*

*People with intellectual disability are also engaged in this life-long journey, from not being in control of the decisions which affect them, from not having influence over their own lives.”*

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## Speak up!

- Speak up! is designed to encourage PWD to speak to someone they trust when they want to:
    - Complain
    - Make a change in their lives
    - Talk about a problem
    - Speak up about abuse or neglect
  - We have reached 775 people across NSW in over 60 workshops – 491 PWD, 256 staff, 28 carers and supporters of PWD – co-delivering with PWID
  - 81% of participants complete anonymous evaluations – 96% stating they think the training is great/good
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## Observations from our Speak up! training

- People with disability want exactly what we want – they just have less opportunities to make it happen
  - People have desires and dreams they want to express
  - People want more experiences, more friends, more opportunities
  - People want more contact with family, friends – they want more quality and depth in their relationships
  - People are frank, and funny, and have great potential to contribute in a variety of ways in our community
  - Direct care staff in services regularly impressed us with the passion, care and consideration they bring to their work
  - Service culture is of utmost importance
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# Observations from our Speak up! training

- People with disability (generally) place a strong degree of trust in their direct support workers
  - Any capacity building work with people with disability should recognise and support the people that surround and support them
  - Make complaints processes truly accessible – there is a lot of talk about ‘accessibility’ for people with disability – but systems and processes should be genuinely easy, results and outcome focussed, fundamentally respectful of people’s rights, and involve speaking directly with helpful, trustworthy and reliable people within an organisation who deliver on their word.
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# How do we empower people with disability to speak up?

- Value people's feedback and opinions
  - Create opportunities to build confidence and self-esteem
  - Provide people with experiences of speaking up
  - Empower people in their daily experiences
  - Honour people's dignity – practice true equality
  - Support self-advocacy and peer mentoring
  - Action what people want.. Service systems must work to accommodate the aspirations and wishes of PWD.
  - **People with disability want exactly what we all want – they just have less opportunities to make it happen**
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# Rights Project for People with Disability

If you have any questions or comments, please contact:

Carol Berry

Principal Project Officer (Rights Project for People with  
Disability)

Strategic Projects Division

NSW Ombudsman

p: 9286 1086

e: [cberry@ombo.nsw.gov.au](mailto:cberry@ombo.nsw.gov.au)

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