PEOPLE'S EXPERIENCE OF THE NDIS

ARTISTS

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ARTISTS OF THE EXHIBIT

Professor John Gilroy

John is a Yuin man from the NSW South Coast and is a Professor of Indigenous Health and Disability, specialising primarily in Disability Studies. John has worked in Disability and Ageing research and community development with Aboriginal communities, government, and non-government stakeholders for most of his life. He is the first person to create Indigenous research methodologies in Disability research.

Professor Paul Rhodes

Paul is motivated to promote the idea that clinical psychology must not limit itself only to the individual or intrapsychic processes when considering how to approach problems of ‘mental health’ and psychotherapy. He feels that it is also critical that we face contemporary developments in philosophy, particularly post-humanism, using art as expression of experience and research in disability.

Jessica Gilroy

Jessica has lived experience of disability and uses art to express her experiences in telling her story of being an Aboriginal woman with disability.
Incarceration of Disability and Aboriginality

THERE IS A HIGH PREVALENCED OF ABORIGINAL PEOPLE WITH DISABILITY BEING UNFAIRLY AND UNJUSTLY INCARCERATED DUE TO THE CRIMINAL JUSTICE SYSTEM NOT PROPERLY EQUIPPED TO SUPPORT PEOPLE WITH DISABILITY, SUCH AS BRAIN INJURY OR FOETAL ALCOHOL SYNDROME. THE NDIS IS NOT PROPERLY ENGAGED WITH STATE/TERRITORY HEALTH AND HOUSING SYSTEMS TO APPROPRIATELY SUPPORT PEOPLE WITH DISABILITY TO LIVE IN THE COMMUNITY AND PREVENT REOFFENDING. PEOPLE WITH DISABILITY HAVE REPORTED THAT THE PRISON SYSTEM PUNISHES THEM AS A PERSON RATHER THAN HELPING THEM WITH ISSUES PERTAINING TO THEIR MENTAL HEALTH AND DISABILITY.
MANY PARENTS OF CHILDREN WITH A DISABILITY REPORTED THAT THEY FELT THAT THE NDIS PLANNING PROCESS HAS THEM RUNNING IN CIRCLES OR TRAPPED IN A MAZE. THEY REPORTED THAT THEY REACHED OUT FOR HELP, BUT NO ONE COULD OR WANTED TO HELP THEM, LEAVING THEM IN TEARS OF DESPAIR. SOME PARENTS REPORTED THAT THEY CONSIDERED, OR FELT IT NECESSARY, TO SURRENDER THEIR CHILDREN TO CHILD PROTECTION AUTHORITIES SO THEY CAN TAKE BETTER CARE OF THEIR CHILDREN WHO DO NOT HAVE A DISABILITY.
HUNDREDS OF PEOPLE HAVE REPORTED THAT THE NDIS PLANNING PROCESS IS HEAVILY FOCUSED ON THE BUREAUCRATIC PROCESS AS OPPOSED TO THE EMOTIONAL AND CULTURAL NEEDS OF PEOPLE WITH DISABILITY. THE MAIN MESSAGE IN THIS ART PIECE IS THAT GOOD WORKERS USE THEIR HEAD, HANDS, AND HEART TO BUILD RAPPORT WITH PEOPLE WITH DISABILITY AND THEIR FAMILIES.
THIS IS A MODERN ABORIGINAL ART PIECE USING THE APPROACH TAUGHT BY THE ARTIST’S ELDERS AND MUM. THE TITLE IS THE SAME TITLE OF A RESEARCH REPORT ON THE LIVED EXPERIENCES OF DISABILITY PUBLISHED BY DR SCOTT AVERY. THIS PIECE IS DEDICATED TO ABORIGINAL CULTURE, WHICH HAS EXISTED FOR MILLENNIA. THIS IS A STORY OF ABORIGINAL FAMILIES BEING INCLUSIVE OF PEOPLE OF ALL DIVERSE ABILITIES. IT REPRESENTS THE IMPORTANCE OF COUNTRY, HEALTH, AND RESPECT FOR THE ENVIRONMENT. THE LEFT SIDE REPRESENTS FAMILIES’ HOMES AND CONNECTION TO MOB AND COUNTRY. THE RIGHT SIDE SHOWS A HUNTING PARTY REPRESENTING GOOD FOOD AND GOOD HEALTH. THE WORKERS INVOLVED IN THE NDIS PLANNING PROCESS MUST UNDERSTAND THAT “CULTURE IS INCLUSION”.

Culture is Inclusion
HUNDREDS OF PEOPLE HAVE DESCRIBED THE FINANCIAL AND EMOTIONAL TRAUMA EXPERIENCED FROM THE NDIS PLANNING PROCESS. MANY FAMILIES HAD TO COVER THE COSTS FOR ALLIED HEALTH AND MEDICAL EXPENSES THEMSELVES TO PROVIDE EVIDENCE TO THE NDIA TO JUSTIFY ITEMS LISTED IN THEIR NDIS PLAN. IN MANY CASES, FAMILIES HAD TO TRAVEL HUNDREDS OF KILOMETRES TO ACCESS THESE SERVICES. MANY FAMILIES REPORTED THAT ALTHOUGH THEY GOT THE EVIDENCE, THE NDIA REJECTED SOME OR ALL THE ITEM REQUESTS IN THEIR PLAN. SOME PEOPLE DESCRIBED THE NDIS PLANNING PROCESS AS LIKE A BATTLE OR A WAR.
MANY ADVOCATES, PEOPLE WITH DISABILITY, AND PARENTS REPORTED THAT PEOPLE STRUGGLING TO NAVIGATE THE NDIS SOUGHT HELP FROM AN ADVOCACY SERVICE PROVIDER. FORMAL ADVOCACY HAS HELPED THOUSANDS OF PEOPLE WHO REQUIRED SUPPORT FROM THE NDIS. ADVOCACY IS ESSENTIAL FOR PEOPLE WITH DISABILITY TO OBTAIN QUALITY SUPPORT DURING THE NDIS PLANNING PROCESS. SADLY, IN SOME CASES EVEN ADVOCACY DID NOT HELP, RESULTING IN PEOPLE LIVING WITHOUT PROPER SUPPORT AND CONTINUE TO STRUGGLE LIVING IN THE COMMUNITY.
Many workers who live in metropolitan regions struggle to understand the experiences of people living in rural/remote regions of NSW. People living in remote and rural areas have different struggles with the NDIS than people living in metro regions. The main differences between metro and rural/remote areas are the road/rail travel distances, the natural environment, employment opportunities, cost of living, and the lack of disability and allied health services in their local regions.
THE NDIS ELIGIBILITY AND ASSESSMENT PROCESS IS HEAVILY WEIGHTED ON THE BIOMEDICAL (THE FUNCTIONING OF THE BODY AND BRAIN) EXPERIENCE OF DISABILITY. THERE IS LIMITED CONSIDERATION OF PEOPLE’S INNER SOUL, SPIRIT, PERSONALITY, SEXUALITY, LOVES, ASPIRATIONS, AND DREAMS. PEOPLE WITH DISABILITY WANT WORKERS WHO ARE INVOLVED IN THE NDIS PLANNING PROCESS TO CONSIDER THE “DEEPNESS” OF PEOPLES’ HEARTS AND MINDS DURING THE PLANNING PROCESS.
THIS PIECE TELLS THE STORY OF MANY PEOPLE WHO GOT “LOST” IN THE NDIS PLANNING PROCESS. WITH THIS ART PIECE YOU NEED TO FOCUS CAREFULLY TO SEE THE STORY. THE STRUGGLE YOU ARE HAVING TO SEE THE DRAWINGS IS LIKE HOW PEOPLE WITH DISABILITY FEEL DURING THEIR NDIS PLANNING JOURNEY. FROM THE LEFT SIDE YOU WILL SEE A DARK FOREST THAT LEADS TO FOOT PRINTS AND WHEELCHAIR PRINTS LEADING TO A BROKEN WHEELCHAIR. IN THE MIDDLE YOU WILL SEE A TREE WITH A HANG-MAN’S NOOSE REPRESENTING HOW MANY PEOPLE FEEL MENTALLY UNWELL. FROM THE CENTRE TO THE RIGHT SIDE, YOU WILL SEE PEOPLE STRUGGLING TO GET THE NDIS DOOR WHICH IS CONSEQUENTLY LOCKED.
THIS TWO-SIDED PIECE TELLS THE STORY OF TWO FRIENDS WHO HAVE BEEN ACTIVE IN THE DISABILITY HUMAN RIGHTS MOVEMENT FOR DECADES. IT REPRESENTS THE IMPORTANCE OF RECONCILIATION BETWEEN ABORIGINAL AND NON-ABORIGINAL PEOPLE WORKING TOGETHER TO LIBERATE ABORIGINAL PEOPLE WITH DISABILITY. RECONCILIATION IS THE JOURNEY PEOPLE TAKE TO RECONCILE THEIR DIFFERENCES TO MAKE THE WORLD A BETTER PLACE FOR EVERYONE. ONE SIDE TELLS PROFESSOR GILROY’S CULTURAL EXPERIENCE OF WORKING ON AND OFF COUNTRY WITH ABORIGINAL AND NON-ABORIGINAL PEOPLE AND BEING MARRIED TO A NON-ABORIGINAL WOMAN. PROFESSOR RHODES’ SIDE TELLS A STORY FROM FINNISH FOLK TALE, THE KALEVALA, WHERE THE DEMI-GOD VAINAMOINEN DESCENDS INTO THE UNDERWORLD, DEPICTING THE CLASSIC JOURNEY OF SUFFERING AND REBIRTH.
THIS PIECE DELIVERS THE MESSAGE THAT MANY FAMILIES HAVE VOICED, “THINK ABOUT IT IF IT WAS YOUR FAMILY” AND “PUT YOURSELF IN OUR SHOES” AND “WE ARE NOT AN NDIS NUMBER”. MANY FAMILIES FELT THAT THE DISABILITY WORKER TREATS THEM LIKE A “TICK BOX”. PROFESSOR GILROY RECOMMENDS THAT ALL WORKERS NEED TO USE THEIR HEAD, HANDS, AND HEART. HIS TEAM DESIGNED A TRAINING PROGRAM THROUGH THE CENTRE FOR DISABILITY RESEARCH AND POLICY CALLED “HEAD, HAND, HEART” AND IS NOW ONLINE.
MANY PEOPLE WITH DISABILITY REPORTED THAT THEY HAVE LOST FUNDS AND SUPPORTS AFTER THE NDIS PLAN REVIEW PROCESS. IN MANY CASES, PEOPLE WERE REQUESTED TO PROVIDE EVIDENCE THAT THEY ARE STILL ‘DISABLED’ DURING THE REVIEW PROCESS. THIS INCLUDES PEOPLE WHO ARE VISION IMPAIRED, PEOPLE WITH CEREBRAL PALSY, AND EVEN PEOPLE WITH A BRAIN INJURY WHICH ARE ALL LIFE-LONG DISABILITY TYPES. THE GOANNAS, DUCKS, AND THE BASS ARE DIFFERENT SIZES AND SHAPES TO REPRESENT THE CHANGES IN THE NDIS PLAN FOLLOWING A REVIEW. SOMETIMES THE PLAN WAS BETTER AND OTHER TIMES IT WAS WORSE. THE SPIDER WEB REPRESENTS THE FEELING OF BEING TRAPPED AND LOST DURING THE NDIS PLAN REVIEW PROCESS.
THOUSANDS OF PEOPLE WITH DISABILITY REPORTED EXPERIENCES OF DISABLISM IN THE COMMUNITY AND IN THE DISABILITY SERVICES SECTOR. THIS ART PIECE TRIES TO CAPTURE THE TWO ARTISTS’ PERSONAL EXPERIENCE OF DISABLISM AND THE STORIES REPORTED TO THEM FROM HUNDREDS OF PEOPLE WITH DISABILITY. THE FEATHERS SHOW HOW WE EMBODY AND CARRY THE HURT OF DISABLISM. THE OLD FEATHERS ARE BROKEN AND WEATHERED TO REPRESENT THE HURT FROM A LIFETIME OF DISABLISM. THE SMALL, SOFT FEATHERS REPRESENT HOW WE FIGHT AGAINST DISABLISM AND CONTINUE TO GROW AND LOVE OURSELVES. THE CENTRAL MESSAGE IS “DISABLISM STOPS WITH WHO YOU SEE IN THE MIRROR”.

The Mirror
Bad Experiences and Good Experiences

This two-sided art piece represents the emotions people expressed to the artists with their experiences of the NDIS planning process. Hundreds of people have reported that the NDIS planning process was well conducted and the NDIS has improved their life significantly. We have also received reports of people who struggle with the NDIS planning process and experience emotions of grief, loss, and trauma.
Family Abuse and Disfunction

This art piece represents the feelings people with disability have expressed relating to their experiences of abuse in the family home, school, and community and disability services. The artists have also experienced abuse directly linked to their experience of disability over their lifetime. The piece has a young person with bruises on their torso hiding their face under a beanie, whilst standing in a thunder storm. Each raindrop is drawn as a tally mark representing the thousands of instances of abuse. The rusted nails and bullet shells represent the internal emotional pain caused by abuse leaving scars.