

***Supporting people with intellectual disability
on society's fringe in the context of the NDIS***



Case Studies

Acknowledgement of Traditional Owners

ARROS (CLA Inc) would like to acknowledge the Traditional Owners of the land on which we live and work. We'd like to acknowledge the Turrbal people of the north of Brisbane, the Juggera of the South and other traditional groups in the surrounding areas.

We'd like to acknowledge all of our ancestors, Aboriginal, Torres Strait Island, and non-indigenous, past and present, for shaping who we are and guiding us into the future.

We welcome you to the community we share.



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Supporting people with intellectual disability on society's fringe in the context of the NDIS

ARROS is a service within Community Living Association that works with young people with an intellectual or cognitive disability who live on society's fringe. They may be on society's fringe because of their experiences of homelessness, the criminal justice system, out of home care, poor mental health or substance use issues. The over representation of people with intellectual disability in these systems is an indicator that their vulnerability to entering these systems is directly related to their intellectual disability. They often have few informal supports, such as friends or family, or mainstream supports. A history of trauma and other social disadvantages may result in complex behaviours that can further isolate them in society, both in terms of informal supports and access to mainstream and specialist supports.

Their vulnerability to trauma, exploitation and other social disadvantages is directly related to their intellectual disability, as is the difficulty they may have in coping with the impact of that trauma, exploitation or social disadvantage.

People with intellectual disability living on the fringes of society have needs that remain unarticulated. There are a number of reasons for this, largely related to their disability. Limitations in intellectual functioning may mean they articulate their needs differently, limitations in social skills may mean they lack informal supports to help them identify and articulate their needs, a desire to 'be like everyone else' may mean they do not identify with the disability labels others may use to define their needs.

Our service model is one of long term intensive holistic outreach with an aim of developing supportive relationships and making linkages to access informal, mainstream and specialist supports.

PURPOSE OF THIS DOCUMENT

The introduction of National Disability Insurance Scheme (NDIS) offers great hope to many people with intellectual and cognitive disabilities. However, NDIS needs to be able to respond to people with intellectual and cognitive disabilities who live on society's fringe. The purpose of these case studies is to share what we at ARROS see as some of the challenges in effectively working with this group and to offer some suggestions about what the NDIS needs to offer this group, based on 10 years of specialist practice in the area.

THE ARROS APPROACH

The young people ARROS supports tend to skirt the fringes of society because they do not neatly fit in anywhere. This may be because of homelessness, or because of lack of informal (or family) supports, or because they have grown up in the care of the State, and exited into a society that does not succeed in meeting their needs. They are unlikely to have succeeded at school: their literacy and numeracy often poor; they often experience little social or personal success; and their prospects of employment will be very limited. Each of these vulnerabilities is directly related to their intellectual disability. They may not receive disability supports because they do not present with obvious physical signs of disability, they have a lack of connection with supporters who could advocate for them or because they may reject the label of disability. Mainstream services often do not respond

appropriately to their needs, dismissing them as non-compliant, unmotivated, attention seeking and other labels that identify the behaviour without attempting to understand the underlying needs that these behaviours are attempting to express or respond to.

This group attract attention when they come in contact with emergency response services, such as police, emergency departments and emergency aid organizations. They are often referred to mainstream services that are generally unable to commit the time required to achieve genuine engagement to build a relationship that might affect lasting change. Many remain isolated from supportive relationships, without hope of social or economic participation, many are chronically homeless and some become incarcerated. Without effective support, social disadvantages increase over time, as people's experiences of marginalization and exclusion increase and their expectations of a good life decrease.

We have been working in this space for over a decade, and have adapted our service provision to respond effectively to young people on the fringe to create:

- places to live
- spaces to belong
- roles for meaning
- a community that welcomes and includes young people from the fringe

ARROS has invested in a culture of reflective practice to learn from experience through documenting and sharing practice as well as developing a professional and experienced staff group.

The following are the key elements of our approach that have proved effective in responding to the range of issues, negative life experiences and barriers to a good life that are typically faced by young people with cognitive disabilities who experience complexities that put them on the fringe.

1. **Pro-active outreach:** Assertive, proactive outreach is needed to connect with young people who may be transient, who are experiencing lots of dislocation due to crisis, to whom services are often seen as unhelpful, interfering, judgemental and oppressive due to previous personal and family history. Services can find it difficult to relate to people whose first response may be hostile, unresponsive or rejecting. Sometimes service design explicitly excludes those who are seen as hostile or unresponsive. Often service design requires people to fit into a model designed for those who can navigate complexity, who can undertake forward planning and follow through on plans made, who have a high level of insight and high capacity to articulate. Assertive and proactive outreach is a necessary option for people whose disability reduces their ability to navigate these complexities, and whose subsequent isolation from supports has led them to live on the fringe.
2. **Skilled workers to build and hold a relationship with the young person:** Building a positive relationship with the young person is paramount to ongoing work. To do this an organisation needs workers with a certain value and skill set. Skilled workers are:
 - committed to establishing a relationship with the young person even though the young person may initially be non-responsive;
 - tenacious in hanging in through chaos and crisis;
 - non-judgmental in holding the value and hope for the young person and not dismissing them because of their behaviour;

- skilled in terms of working through chaos;
- courageous in holding in the face of behaviours that may be personally challenging and sometimes physically threatening;
- insightful in understanding the level of anxiety, or fear, or trauma that is prompting the person's survival responses;
- creative in seeing people's strengths and gifts;
- hopeful in supporting them to express those gifts;
- enabling in supporting young people to develop new supportive relationships in the community.

We have found that such workers need significant training and ongoing supervision and support.

3. **Flexibility:** Support with young people needs to be flexible, responsive to both stated and unstated needs, and easily shifted from proactive planned work to crisis response. It is also important to periodically prioritise work to build, strengthen, maintain or repair the worker's relationship with the young person. A flexible approach includes:
 - holding strongly to a vision of a good life for someone while holding very lightly to your planned process of how to achieve it: rather responding flexibly to the needs of the moment;
 - recognising that young people may have difficulty articulating their needs clearly so the worker needs to recognise and respond to this without a clearly articulated argument from the young person. Responding to this may begin with taking the lead in supporting the young person to imagine and express their vision for a good life, and planning the steps towards this;
 - being responsive to young people in crisis. ARROS operates an after-hours telephone service where young people can seek help on evenings and weekends;
 - being responsive to changing the time, date, length, and purpose of an outreach at any time up to and including after the proposed start time.
4. **A commitment and ability to engage with the people in the young person's life:** young people may have family or peers in their life who are supportive as well as people in their lives who place them at further risk. Workers required the ability and commitment to work with these relationships to hold and enhance those aspects that support the young person and to assist young people to promote safety in those that increase risk. This may mean supporting people to develop risk averse behaviours, safe relationship skills, create new relationships and end those relationships that no longer serve them.
5. **Capacity to respond holistically across the range of areas that affect people's lives:** create opportunities for people with cognitive disability on the fringe to belong, including somewhere safe to live, someone to call on, something meaningful to do and places to feel accepted. The work includes facilitating links and positive relationships with service providers and can involve undertaking advocacy on the person's behalf to ensure they have access to services in health, housing and other systems. Building the capacity of key community members to understand the person's disability and to respond positively is essential to social inclusion and creating opportunities to work or engage in meaningful activities with the support required to sustain these activities.

Table: Service responses designed to meet the needs of this group

ARROS Service Response	Elements/characteristics of day to day practice specific to the needs of this group
1. The need for proactive assertive outreach	<ul style="list-style-type: none"> • Recognise that people on the fringe have extreme distrust of services and of people in society generally. • Build relationships slowly, gently, and highly respectfully. • Wait for people: be patient. • Understand that there may be a lot of missed appointments. • Actively follow up with people, making appointments, dropping in, spending a significant amount of time with someone to demonstrate your desire to connect with them. • Engage in a person's home or community space rather than an artificial environment such as an office. • Spend time in people's presence with the aim of relationship building rather than a specific outcome. • Persist to overcome people's reluctance to engage with a service
2. Experienced workers that are skilled, qualified, well-resourced with access to training, opportunity for deep reflection and supervision	<ul style="list-style-type: none"> • Strive for continuity of relationship between key workers and constituents to establish trust and long term engagement with supports. • Maintain a stable workforce for continuity. • Review practice approaches to align with people's needs, overcome barriers and develop creative responses. • The need for experienced and trained workers. • One worker responding across a range of areas means they develop a much better insight into people's lives. By truly knowing and understanding people, being alongside them, we are privy to seeing the bigger picture, allowing us to advocate better for a person's needs and develop more appropriate and person centred goals. • Therapeutic work occurs alongside practical support, for example whilst doing grocery shopping, or cleaning/tidying a hoarded home. • Workers skilled in community development will find opportunities arise from their own networks and the more we support ongoing relationships with community the more we can create community for our constituents.
3. The need to offer flexible support, both with time and with content of work	<ul style="list-style-type: none"> • Support needs can fluctuate due to the person's capacity to engage in different things, e.g. sometimes the focus will be on crisis response, sometimes proactive work, sometimes the worker will just need to engage to hold the relationship. • Hold connection with people (in whatever form available) as they transverse different geographies due to crisis, transience etc. • Tailor every plan – be responsive, not formulaic. • Listen to people and plan with people who struggle to articulate their support needs. • Change appointment times when the young person has other priorities, eg is under the influence of substances, is experiencing a life crisis or is prioritising a new relationship. • Maintain contact over time, but recognise that contact intensity fluctuates depending on the person's current life circumstances.

	<ul style="list-style-type: none"> • Adapt interventions as they are implemented. • Be responsive to the present needs of the person, and flexible to allow people to continually change their end goals as they develop understanding of the situation and the potentials. • Meet with significant others outside of work hours where needed, e.g. volunteers and community members in the evening after they finish work.
<p>4. The need to engage with significant others, both those who provide support and those relationships that increase risks, exploit or cause further difficulty or continue to disappoint the person</p>	<ul style="list-style-type: none"> • Young people ARROS supports have a lack of informal supports (if they had supports they would not be at such high risk of homelessness). • Value and promote interdependence. • Build resilience. • Promote understanding in the community about cognitive disability. • Challenge understanding that can vilify the person who needs the support e.g. seeing a person as 'non-compliant', 'self-selecting out', 'irresponsible', 'lazy', 'unable to prioritise'. • Acknowledge the importance of other people and put energy into those significant others in line with the importance they have in the young person's life. • Support significant others as this creates more support than we can quantify e.g. one volunteer has a constituent stay at her home 3 days per week; good relationships with support workers has lead to inclusion of young people in several community spaces such as community gardens, local cafes.
<p>5. Capacity to respond holistically</p>	<ul style="list-style-type: none"> • Establish a positive relationship as this is crucial to achieving any outcomes. • Learn and understand what the person wants, needs, and what barriers they face (especially if their verbal reporting does not give a good indication of this): <ul style="list-style-type: none"> ○ to be there to respond when crisis presents ○ to be there when opportunity for proactive work presents • To understand the impact of their disability. • Continuity of care/work means that things are not lost in communication and that someone holds responsibility for ensuring important goals stay on the agenda. • Develop a key relationship that lasts over time rather than having a succession of workers • A key relationship can respond holistically, rather than dividing work between specialist response providers.

“You guys are alright... I know you’re trying to help”

Charlie reflecting on the supportive relationship he has built with ARROS after a long history of being under restrictive practices in correctional settings, and in trouble with the law since living in community settings.

NDIA Intellectual Disability Reference Group Topic Focus:

Participants with complex behaviour

Planning and implementing support where participants lack effective informal support

Decision making and participants with cognitive impairment

Creating a positive vision for participants with intellectual disability

Practice Topics

Pro-active outreach

Skilled workers to build and hold a relationship with the young person

Flexibility

A commitment and ability to engage with the people in the young person’s life

Capacity to respond holistically

Referral: Charlie is a 25 year old man with an intellectual disability who was referred to ARROS by Disability Services. He was under a forensic order as a young person and consequently grew up in an institution. Life outside the institution was difficult. He was sleeping on the streets with his pets, had no money for food and had a high level of involvement with the criminal justice system. Charlie was easily triggered by anxiety and frustration, which often lead to aggressive outbursts, where Charlie would use verbally and physically threatening behaviours. This further exacerbated his situation, reducing options for accommodation, increasing restrictions on his communication with Public Trust, and negatively influencing interactions with police.

- Risk Factors:**
- Homelessness and poverty.
 - Legal and criminal justice issues.
 - Exploitation—physical, emotional, financial and sexual exploitation.
 - Mental health issues, anxiety, trauma.
 - Social isolation—no informal support.
 - Challenging behaviour – significant difficulty with emotion regulation, leading to rejection, exclusion, criminal justice issues.
 - Safety – physical assault from others.

- Engagement**
- Engagement included meeting with Charlie and doing a lot of listening. Charlie would sometimes ask us to bear witness to his life, for example call us on the phone to listen to interactions between himself and police or community members. This was an attempt by Charlie to help us understand the complexity of his life and the extreme challenges he faced.
 - There was very little opportunity for movement in the early days and it was just about making plenty of contact, whenever he was open to it, to build a working relationship.
 - Provided material resources—often a meal as a starting point to engagement, as he may not have eaten for days. A meal met some of his basic needs, while assisting him to regulate his emotions.
 - Developing relationships with key formal and informal support and assisting Charlie to manage these relationships to prolong their longevity. These

included:

- informal supports, e.g. local community members, neighbours;
- pet carers;
- police;
- psychologist;
- Department of Housing;
- Public Trustee;
- Disability Services.
- Workers needed to balance risk (to their own safety) with the intention to develop their relationship with Charlie.

Planning

- Provided intensive training for workers around trauma and attachment, as well as extensive supervision around how to keep safe (emotionally and physically) and support around planning and implementation of goals.
- Accommodation support—supporting him to sleep rough as safely as possible, then finding crisis accommodation and later, long-term housing options.
- Developing a positive behaviour support plan.
- Building skills for resilience, including self-care strategies for Charlie.
- Proactively supporting new relationships for Charlie. Recruiting and supporting community members to pet sit for Charlie. This allowed Charlie to access hostel accommodation and not sleep rough.
- Relationships—modelling and supporting mutuality in relationships, and supporting Charlie to recognise and respond to exploitation by others.
- Safety in community—to support Charlie in his responses to those in the community who would seek to inflame him.
- Developing and maintaining relationships between Charlie and other services to allow Charlie to actively engage in meetings and access these independently.
- Safety of animals, e.g. RSPCA, Police, community members—creating options for his pets that provided for their needs for food, shelter, veterinarian care. Involving RSPCA with regard to the care of his animals, police in response to complaints about his treatment of animals, and community to look for options to support him in his care of the animals, i.e. pet sitters.
- Finances— to rebuild relationship with Public Trustee.
- Legal support—to access and advocate to legal aid.
- Meaningful use of time and role in the community—using Charlie's skills, values and passion.

Implementation

- Key Worker and Support Worker.
- Active support.
- Crisis intervention.
- On-call support.
- Advocacy to police and lawyers.
- Teaching of strategies to keep safe.
- Positive behaviour support—established and implemented boundaries while maintaining the relationship with Charlie, i.e. many attempts at implementing boundaries resulted in escalation of challenging behaviour. A key boundary issue was that Charlie would be reluctant to let workers leave even after several hours of support. The reconnection work that occurred after instances where workers felt highly challenged by Charlie's behaviour was the key to the continuation of the working relationship.
- Teaching of and provision of opportunities to build resilience.
- Education and role modelling for service providers around effective work with

Charlie.

- Community connections with and for Charlie.
- Extensive supervision and support of key worker and support worker.

Outcomes

Charlie has been engaged with ARROS for over 12 months.

- Social Participation—Charlie is participating in peer advocacy events.
- Accommodation—Charlie has acquired permanent housing in the private rental market (stable for last five months).
- Legal problems—decrease in critical incidents and criminal justice matters.
- Finances - attends meetings with the Public Trustee to plan toward independence.
- Disability Services have recognition of Charlie's support needs and have increased funding to Charlie.
- Greater self-control - when Charlie is escalated it is still difficult for him to self-regulate, however he now has much greater control over his actions. He uses the resource developed for him by ARROS, the 'Calm Down Kit'. This is proving effective in helping him to respond to escalation.

Conclusion

- Charlie is part of a group of people who are at risk of missing out on NDIS support, because they struggle to engage successfully with any systems or voices of authority. This group will likely be excluded from any formalised supports and picked up by tertiary systems such as hospitals, prisons and emergency services.
- Charlie openly identifies himself as having a disability but often those around him interpret his behaviour in different, less supportive ways. Without supportive people to help others understand Charlie's behaviour, he can be named as a troublemaker and miss out on supports that would otherwise be available to him.
- ARROS provided proactive outreach to a person with complex and challenging behaviour who was difficult to engage and who would not have easily negotiated an intake assessment process.
- Assertive outreach required making long trips to meet with Charlie wherever he was, spending long periods of time listening to his stories, and workers establishing themselves as useful to Charlie by providing material resources, such as food for him to eat during outreach. During the initial relationship building period, workers needed to be very careful about what expectations they set up with Charlie, as he was very aware of changing rules, and this was a point of conflict.
- Relationship building with Charlie needed to be time rich: spending significant amounts of time with him, helping him to trust that you were genuinely interested in him as a person and were on his side. It needed to be highly respectful of Charlie, while balancing the need for workers to keep themselves safe, both physically and emotionally.
- ARROS worked proactively to develop a positive supportive relationship with Charlie, who exhibited challenging behaviour, including frequent aggressive outbursts. To achieve this required the time and capacity to listen and plan when he had difficulty regulating his emotions and articulating his needs.
- This work required skilled and well-supported workers who had the knowledge to implement trauma informed practice to support positive behaviours at all stages of escalation from self care practices to incidents where staff's physical and emotional safety were compromised.

- ARROS provided flexible support to ensure that we continued to be of use to Charlie: being responsive to Charlie's stated needs on each outreach; beginning each outreach where Charlie was at; balancing the need to respond to crises with the need to work proactively to create long lasting change; operating an after hours phone service for emergency weekend and evening support; developing creative responses and working doggedly to make them eventuate.
- Workers needed to build relationships with the community, to introduce others who may help to address some of Charlie's needs. Workers needed to support significant others through all stages of relationship with Charlie, from beginning, to addressing challenges, to rebuilding after issues and ending.
- Workers needed to build a significant number of relationships with service providers, decision makers and resource holders, as Charlie's behaviour often prevented his success in navigating systems, speaking with people who have authority or getting results when there is any form of setback or rejection.
- ARROS displayed creativity and innovation in behaviour support and responding to trauma responses by developing a new resource, the "Calm Down Kit". This approach transcended the restrictive practices that are often used to control rather than support people with complex and challenging behaviour.
- Creative responses supporting him to get to the end goal of having a home where he lives with his pets.

"You guys are alright... I know you're trying to help"

- Charlie

"It's ok, I trust you"

Moving from being a young person who was extremely difficult for services to engage to a young person with a significant trust in her worker, and those associated with the service.

NDIA Intellectual Disability Reference Group Topic Focus:

- Planning and implementing support where participants lack effective informal support
- Participants with complex behaviour

Practice Topics

- Pro-active outreach
- Skilled workers to build and hold a relationship with the young person
- Flexibility
- A commitment and ability to engage with the people in the young person's life
- Capacity to respond holistically

Referral: Sarah was referred by Child Safety in 2012, upon nearing the end of her foster care transition, with an individualised funding package to support her in that process.

Sarah had a history of not engaging with any support staff, due to poor experiences with service providers. Sarah experienced multiple traumas with her family of origin and foster families whilst placed under Child Safety guardianship. Sarah was living with her mother, against Child Safety advice. Sarah's mum also had an intellectual disability and struggles to protect Sarah from abuse from other significant adults within the home environment. Sarah sometimes experienced primary level homelessness, sleeping in the bag racks of her school grounds.

Sarah had been linked with many services including those focussing on school, family, mental health and disability, but she was frequently discharged for 'non-engagement'. Child Safety was also unable to effectively engage with her resulting in their inability to develop a transition plan.

- Risk Factors:**
- Homelessness—very high risk of long term homelessness.
 - Domestic Violence—physical and psychological abuse.
 - Poor physical and mental health.
 - Exploitation—at risk of financial exploitation, sexual exploitation, emotional exploitation, particularly when under the influence of substances
 - Drug and alcohol abuse including incidents of being forcibly injected with drugs.
 - Disconnection with her son in the care of the State.
 - Disengagement and isolation—there was a long period of time after receiving the initial referral from Child Safety that Sarah would not engage with ARROS. Sarah had not actively engaged with any support agencies prior to ARROS and reported that she did not trust workers.
 - Social isolation—if the relationship with her family broke down, Sarah was at risk of becoming highly socially isolated. However, maintaining a connection with her family increased other risks in her life.

- Engagement**
- Initial engagement was based around building rapport, providing information about the potential support ARROS could provide whilst empowering Sarah's self-determination.

- Engagement - involved significant others to build Sarah's confidence, including her mother, stepfather, and partner. It was critical to foster a relationship with these individuals whilst holding strong boundaries that the work was to be centred on Sarah's decisions and goals.
- Outreach - this often involved hours of waiting for her, missed appointments, long periods of no contact despite continually reaching out, and ability to respond when opportunities for connection presented.
- Not responding negatively to Sarah's rejections and being highly responsive and flexible during each engagement as Sarah did not follow through on any plans made to work towards outcomes.
- Flexible around location and time, e.g. sometimes 'hanging out' in safe parks as a way of being away from relationships and other stressors in the home.
- Advocated with Child Safety regarding access to her son. Advocated with Department of Housing around access to appropriate accommodation for herself and her son and tenancy issues, such as whether she was still eligible for ongoing housing considering she had 'abandoned' her home when escaping a domestically violent situation. Advocated with domestic violence services about her access to their safe houses (as a person with a disability, she was considered to be a high risk client for them in terms of sharing the locations of safe houses).

Planning

- Proactive outreach plans - dropping in unannounced to create an opportunity for connection. Planning was very flexible to engage Sarah as she did not follow through on plans made.
- Continually reaching out to Sarah via text and phone calls despite lack of response / minimal response from her.
- Gaining resources, eg accommodation.
- Building Sarah's capacity to identify her needs and to engage with services and systems.
- Exploitation - provide a protective and safe relationship to model healthy relationships and boundary setting, and address issues of exploitation in her other relationships.
- Capacity building with Child Safety and services - featuring time intensive mediation and information sharing.
- Positive relationships with her significant others.

Implementation

- Key Worker.
- Outreach - dropped in unannounced to create an opportunity for connection. Visits could last from between two minutes to five hours depending on Sarah's situation, mood and need.
- Provided continuity and flexibility of outreach, even after months of rejection by Sarah, allowed for space and time to build rapport, show care, build trust, identify need and create positive, healthy relationship experiences.
- Addressed issues at Sarah's pace and advocated with others regarding:
 - drugs and alcohol;
 - housing;
 - relationships;
 - isolation from support and friendship;
 - contact with her son in the care of the State.

Outcomes

- Sarah is no longer a victim of domestic violence. She left a very violent intimate relationship and stayed away and is now engaged in a non-violent relationship.
- Less exploitation in the family. She created some healthy boundaries to protect herself in her family of origin.
- Long periods with no drug use.
- Sarah is in safe and stable accommodation - no drug dealers / users accessing her home space, therefore no property destruction from drug related violence.
- Social participation - Sarah has developed some positive relationships with young people in her peer group through ARROS events. In these relationships, she has been able to take on the role of a responsible adult, providing wisdom and guidance to others around issues of parenting and relationships.
- Connection with her son - regularly attends contact visits with her son, and continues to develop her ability to respond to Child Safety requirements.
- New skills - she is open to receiving information and support and will share and reflect on her life experiences and future plans.
- Accessing support as required - Sarah is now comfortable to ask for support, engaging with multiple services and support workers.
- Health - Sarah's physical and mental health has improved.

Conclusion

- ARROS has provided proactive outreach over many months to overcome this person's reluctance to engage with a service.
- To achieve this required the service to support the worker to be persistent, creative and flexible (rather than working on constrained appointment times), to listen and eventually identify a need to work together to build a relationship to support planning. The results were life-changing, person centred outcomes.
- This work takes time to build rapport, show care, build trust, identify needs and create positive, healthy relationship experiences. Taking the time in building the relationship is pivotal when people have a history of not actively engaging with support agencies.
- This intervention supported this person to develop a positive vision for her life and averted her previous trajectory of injury or death from domestic violence, or jail.
- The worker who undertook this work needed a set of professional skills that allowed them to respond appropriately and proactively when opportunities arose, e.g. having the knowledge of how to advocate with systems, how to respond to disclosures of abuse, and how to support someone to escape a violent relationship.

"It's ok, I trust you."

- Sarah

"I don't like being told what to do"

Sam's story of moving from being a young man who confabulated all kinds of stories to present a particular image, to being someone who can share accurate information without fear of rejection.

NDIA Intellectual Disability Reference Group Topic Focus:

- Planning and implementing support where participants lack effective informal support
- Decision-making and participants with cognitive impairment
- Creating a positive vision for participants with intellectual disability
- Participants with complex behaviour – due to confabulation, alcohol abuse, domestic violence, exploitation from neighbour

Practice Topics

- Pro-active outreach
- Skilled workers to build and hold a relationship with the young person
- Flexibility
- A commitment and ability to engage with the people in the young person's life
- Capacity to respond holistically

Referral: Sam is a 28 year old male who has an intellectual disability. Sam was referred to ARROS by Child Safety in 2002. He was residing with his father who also has an intellectual disability.

In Sam's teenage years, he experienced sexual abuse, substance abuse, very poor household hygiene, and numerous examples of verbal, financial and physical assault by community members.

Before the engagement with ARROS, a number of family services experienced significant difficulties engaging with Sam and his father, due to Sam's lifestyle and his tendency to confabulate stories to demonstrate his worth. Services consequently decided to withdraw their support due to Sam and his father's alleged 'non-compliance'.

Sam was being routinely exploited by a neighbour, who would encourage Sam to engage in criminal activities (theft, break and enter) including violence (e.g. threatening his father for money).

Sam is a very affable and engaging young man and wants to be liked and have fun, to the point of responding to offers of 'friendship' with no thought of the cost to himself.

- Risk Factors:**
- Homelessness.
 - Personal and household health and hygiene concerns.
 - Relationship conflicts with significant others.
 - Social isolation.
 - Impulsivity.
 - Exploitation - financial and sexual abuse.
 - Substance abuse.
 - Physical safety.
 - Legal issues.
 - Intergenerational poverty.

Engagement • Initial engagement with Sam required perseverance over an extended period

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- Better self control - increased capacity to manage his alcohol consumption.
 - Reduction in seizures due to support in managing medication.
 - Less frequent critical incidents around his personal safety.
 - Economic participation - Sam has worked for a few community organisations and now has a private car detailing business.
 - Increased capacity to regulate his emotions and impulsivity.
 - Developed supportive relationships with a volunteer and community members.
 - A supportive relationship with his father - Sam now has a relationship with his father where he seeks emotional support and social engagement rather than financial support. There is no exploitation in this relationship any longer.
 - Finances - increased capacity to manage his money.

- Conclusion**
- ARROS provided a flexible and long-term outreach approach which allowed Sam to feel safe, and to gradually develop a relationship of trust with this allegedly 'non-compliant' person and his father, when other services had given up.
 - This work required flexibility to work out-of-hours and long timeframes to develop relationships, including active listening to interpret Sam's true goals without becoming blindsided by the confabulation that he used to present himself as a competent and worthy person.
 - It required a commitment to getting to know the significant others in Sam's life: his father, to understand the reality of the physical abuse that was occurring from Sam to his father; his neighbour to understand the abuse and exploitation that was occurring from his neighbour towards him.
 - The work required flexibility to respond to Sam's stated immediate issues rather than stick to plans made.

"I have been with ARROS forever and the workers can't tell me what to do but they can make suggestions. I don't like being told what to do!"

"ARROS workers are pretty fun and easy to talk to"

- Sam

"I talk now"

A journey from being effectively mute through fear to using her voice to advocate for others.

NDIA Intellectual Disability Reference Group Topic:

- Promoting equity of access to the NDIS
- Planning and implementing support where participants lack effective informal support
- Decision-making and participants with cognitive impairment
- Participants with complex behaviour
- Creating a positive vision for participants with intellectual disability
- parents who have an intellectual disability

Practice focus:

- Pro-active outreach
- Skilled workers to build and hold a relationship with the young person
- Flexibility
- A commitment and ability to engage with the people in the young person's life
- Capacity to respond holistically

Referral: Sharon is a 33-year-old woman with an intellectual disability who was referred to ARROS in 2003. Her daughter (born 2002) was taken from her at birth and placed in the care of the State.

At the time Sharon came to ARROS, she was living with her sister who also has an intellectual disability, and her boyfriend who had substance use issues. She had an open infected leg wound which was not receiving any attention. She was not engaged with any services.

Sharon was reluctant to communicate, and would sit mute during visits and deferred to others. Her mobility and speech issues made communication difficult - people often mistook her slurred speech as drunkenness.

She visited her daughter regularly, but did not understand why her daughter couldn't live with her. She was angry that her aunt and uncle cared for her child whilst she missed out. Child Safety had imposed strict requirements on the conditions of Sharon's access visits.

- Risk Factors:**
- Suspected mental health issues which were undiagnosed at the time.
 - Loss of contact between mother and child due to Child Safety concerns.
 - Poor verbal communication.
 - Serious health concerns due to poor hygiene and lack of medical attention.
 - Social isolation.
 - Sexual and financial exploitation and victimisation.

- Engagement**
- Initial engagement with Sharon focussed on supporting and advocating for her as a parent.
 - Priority support provided to Sharon to seek urgent medical attention for infected wound.
 - Engagement over time aimed to build knowledge about her communication needs leading to her increased willingness and confidence to allow other people into her life, to build supportive connections with community activities and to explore options for support and other services.

- Engaged with the household to address relationship difficulties.
- Engaged with significant others in Sharon's life - friends and family members.
- Engaged with services including:
 - Child Safety regarding contact visits with daughter.
 - Police - victim of crime incidents.
 - Disability Services for eligibility assessments to access funding for ongoing support.
 - GP - health issues.
 - Psychiatrist - mental health support.

Planning

- Contact visits with her child - support to communicate with Child Safety and to attend contact visits in NSW (8 hr commitment per visit).
- Accommodation - Sharon was staying with friends and family, often relying on their support whilst also being vulnerable to exploitation within these relationships.
- Independent living - to support her with personal hygiene, cooking and cleaning.
- Healthy relationships - to support Sharon in making meaningful new connections and to retain existing or rebuild connections.
- Protective behaviours - to address vulnerability to exploitation.
- Social participation and meaningful use of time - to address her lack of connections outside of her family and friendship groups.
- Decision-making - to build capability by supporting her to process options and make choices e.g. how decisions were being made for her.
- Adult Guardian - to help Sharon make life decisions.
- The Public Trustee - to safeguard against financial exploitation.
- Health - to support Sharon to access medical support.
- Community access support - to attend access visits, and support her engagement in community life when distance and lack of public transport prevented it.

Implementation

- Key worker - established supportive relationship, crisis intervention, on call support, outreach visits as well as regular phone calls.
- Support to access health services - supported Sharon to engage with a regular doctor (support prior to, during and after appointments).
- Advocacy - with Child Safety, advocating very strongly, at times, for contact to continue whilst supporting Sharon to meet requirements regarding hygiene and behaviour during access visits.
- Advocacy and capacity building to services - Disability Services, Service Providers, Department of Housing, Adult Guardian, The Public Trustee.
- Decision-making - supported Sharon to increase her capacity to process information and to develop strategies to address acquiescence.
- Social participation - linking Sharon with a community access service for access to socially inclusive activities as well as advocacy and educational opportunities. They also assist in providing for Sharon's emotional wellbeing. Sharon attended a line dancing group for several years. Sharon is an active member of her local church, which also provides opportunities for social inclusion, spiritual development and having a role in her community.

Outcomes

- Sharon has sustained involvement with ARROS (over 10 years) and has strong

relationships with a number of workers and the organisation.

- She visits her daughter with the support of ARROS four times a year.
- Accommodation - now has stable housing through the Department of Housing.
- Social participation - Sharon has involvement with a range of social activities which has greatly increased her network of belonging and support.
- Health - Sharon regularly visits her local GP and has connections with staff.
- Specialist support - a successful connection with a sexual assault counsellor.
- Finances - Sharon has savings with the Public Trustee.
- Sharon is more able to identify and avoid exploitation and victimisation.
- Sharon is more confident to communicate, e.g. Sharon gave a speech to a government enquiry to advocate for her and others with an intellectual disability - highlighting the inability to effectively respond to their own needs.

Conclusion

- Assertive outreach was required to support Sharon to access service support
- Planning and implementation of support (including decision making support) required that ARROS develop an ongoing working relationship with Sharon.
- To achieve this required slow and careful engagement to build trust with someone who was extremely distrustful of services. It took a significant amount of time and persistence to connect and build relationships and to listen for this person's goals as well as responding to crises along the way. The complexity of Sharon's behaviour included her initial refusal to verbally communicate, her reluctance to attend to personal hygiene, her anger at Child Safety, her difficulties in resisting the exploitation of others. To work through these issues required skilled and supported workers.
- Sharon's workers held a positive vision in spite of difficulties and assisted her to become linked to her aunt, to hold relationship with her daughter, to more effectively deal with people who exploited her, to speak for herself and others.
- Without support it is highly likely Sharon would have lost contact with her daughter.

"I talk now"

- Sharon

“The world is a much better place to live”

The story of someone who was set to move directly into the homeless person’s system on leaving out of home care.

NDIA Intellectual Disability Reference Group Topic:

- Promoting equity of access to NDIS
- The definition of intellectual disability
- Planning and implementing support when participants lack effective informal support

Practice focus:

- Pro-active outreach
- Skilled workers to build and hold a relationship with the young person
- Flexibility
- A commitment and ability to engage with the people in the young person’s life
- Capacity to respond holistically

Referral: Amy is a 17 year old woman with an intellectual disability (linked to foetal alcohol syndrome) and mental health challenges. She was referred to ARROS in 2010 by Child Safety to support her exit from the care of the State. At that time Amy and her former foster mother felt pressured by Child Safety to exit into homeless accommodation.

- Risk Factors:**
- Homelessness - no prospect of stable and safe housing.
 - Mental health deterioration.
 - Exploitation - both financial and sexual.
 - Relationship issues with family of origin and exploitation, eg. Amy’s sister tried to arrange a marriage with a person on a student visa.
 - Early pregnancy - a risk factor for young people with an intellectual disability, who often become parents without a plan or choice.
 - Lack of engagement in positive social options could have led to poor social outcomes.

- Engagement**
- Key worker engaged with Amy and former foster mother, and supported them to explore accommodation options. They quickly realised that they could keep living together as long as they were both happy with the arrangement.
 - Engagement with services - to develop financial safeguards and decrease exploitation risks by assisting Amy to approach the Public Trust to support her management of her money.
 - Community support agencies - engaged to achieve her personal goals and develop options for meaningful use of time.

- Planning**
- Accommodation - to continue living with former foster mother for a few years after exiting from the care of the State, then to move to semi-independent living through Young People’s Homeshare (a live-in mentor program through CLA).
 - Building close supportive relationships - with former foster mother and her family, and introducing role models (volunteer worker and live-in mentors).
 - Safety in relationships - to set boundaries in intimate relationships and relationship with family of origin.
 - Support to help Amy manage her mental health, in particular, anxiety.
 - Decision-making for self-determination - to increase Amy’s capacity to:
-

- transition from former foster home to own unit with a live-in mentor;
- establish a home-share agreement (and regular follow-up);
- manage her finances;
- keep her house hygienic (with support from a live-in mentor);
- be able to set appropriate boundaries.
- Social Participation - to address meaningful use of time issues, barriers to participation (e.g. fear of using public transport) and create valued roles in connection to her personal goals.
- Capacity building - supporting community to understand and support Amy e.g. to access Certificate level training at TAFE, and to volunteer at her local Early Learning Centre.

- Implementation**
- Key worker - focussed on building a stable supportive relationship with Amy and building support around her through:
 - building a relationship with former foster mother
 - building a relationship with family of origin
 - recruiting a volunteer worker
 - recruiting a live-in mentor.
 - Supervision of support people - volunteer worker, live-in mentors and support to former foster mother.
 - Social participation - supporting Amy to achieve her personal goals and have a valued role in childcare by building a relationship with the manager at local Early Learning Centre.
 - Increase mobility for greater independence - following six months of intensive support from the volunteer worker and the key worker, Amy is now able to travel independently using public transport
 - Advocacy :
 - QCAT (financial administrator);
 - Department of Housing (for Amy to get a two bedroom unit in order for a live-in mentor to move in with her);
 - Centrelink (successful application for DSP);
 - TAFE (classroom support);

- Outcomes**
- Stable and supportive network of people - Amy has met with her volunteer worker on a fortnightly basis for the last 5 years; she keeps close contact with her former foster mother.
 - Increased boundaries within relationships with family of origin, e.g. Amy was able to exit (with assistance) from the arranged marriage scenario.
 - Stable accommodation - Amy has successfully transitioned from the care of the State into the live-in mentor program averting homelessness.
 - Increase in independent living skills - Amy has been supported by live-in mentors for the last two years. Both mentors maintain a relationship after the cessation of the formal role. This has enhanced Amy's circle of natural supports.
 - Financial management and increased autonomy - Amy now has significant savings, which she is planning to use to purchase a home in the future.
 - Economic participation - completion of Certificate 3 in Childcare, and attained a casual position as a Childcare Worker at a local Early Learning Centre
 - Social participation - Amy actively participates in many ARROS peer events.

- Conclusion**
- Young person was being told to remove herself from a supportive environment into the homeless person's system.
 - To build a trusting relationship took time.

- ARROS provided the flexibility to respond to crisis but also the trust that had been built up allowed her to share about the arranged marriage.
- There is a need to work with significant others (so that the service is aware of exploitation and is able to provide support to significant others to respond appropriately and supportively to the person in need).
- Building of new relationships and holding of old relationships.
- ARROS supported informal support to stay in place.
- Supported a positive vision, including a mentor, a live-in mentor, TAFE, jobs, house of her own.
- Engaging with significant others.
- Engaging with the wider community.

*"The world is a much better place to live in because of the work
you are doing"
- an in-house mentor*

"I have no more court days now!"

Sally's reflection that at one point, she had completed all her court attendances. Up until that point, she had faced charges for many years due to an accumulation of petty and criminal offences.

NDIA Intellectual Disability Reference Group Topic Focus:

- Promoting equity of access to the NDIS
- Participants with complex behaviour

Practice Focus:

- Pro-active outreach
- Skilled workers to build and hold a relationship with the young person
- Flexibility
- A commitment and ability to engage with the people in the young person's life
- Capacity to respond holistically

Referral: Sally is a 19-year-old young woman with a cognitive disability and mental health issues (including self-harming and suicidal behaviour, depression and bi-polar disorder). She was a client in Child Safety and Disability Services and a number of youth support services (for short periods).

In 2013, at the age of 17, Sally was referred to ARROS to support in her transition from the care of the State. At the time she was the sole tenant in a highly tailored 24 hour supported accommodation arrangement.

Sally experienced high anxiety and significant difficulties communicating with professionals (e.g. GP) and spent her days locked in her room. Youth workers reported critical incidents almost daily, including self-harm behaviour, suicide attempts, overdosing on prescription medication, and drug abuse.

Sally was effectively denied access to mainstream services and a chance at creating a positive life vision for herself.

Sally's reported life goal was to become a gangster drug dealer.

- Risk Factors:**
- Homelessness.
 - Suicide—risk of overdose.
 - Legal and criminal justice issues—charges include DVO against her from her mother, drug related charges (including possession of drugs and implements, petty theft, car theft, travelling without concession card, assault of a youth worker). Her trajectory, should she continued to face charges, was imprisonment.
 - Mental health issues—self-harm and suicidal behaviour, depression, bi-polar disorder
 - Social isolation and severe family dysfunction leading to mental health deterioration. Sally responded to any opportunity to have relationships with her family of origin, however family engagement usually led to financial exploitation, increased drug use, engagement in criminal activities, and was often a precursor to self-harm and suicidal behaviour.
 - Emotional and financial exploitation from the family of origin.

Engagement	<ul style="list-style-type: none"> Engaged in a flexible, long-term and creative approach to establishing a safe and trusting relationship for Sally to disclose her feelings and personal information gradually, including participation in her preferred activities such as drawing and rapping to explore her goals. Engaged service providers - to build a bridge to effective and purposeful relationships with service providers (e.g. Child Safety, Disability Service, Employment Agencies, G.P., legal services). Engaged with significant others - to build more appropriate relationships (e.g. family of origin) at the early stage of transition.
Planning	<ul style="list-style-type: none"> Accommodation - to achieve stable accommodation and liaising with youth accommodation service providers (e.g. youth shelters, Dept. of Housing & Community Housing). Establish goals and plans for meaningful roles within the community. New supportive relationships—to establish and strengthen positive support networks in Sally's life by recruiting volunteers, support workers and placement students. Decision-making support - in complex situations e.g. challenging exploitative relationships in Sally's life, including in her family of origin. Self-care - to support Sally to recognise and process complex emotions and to develop self-care strategies. Physical safety - to create a mutually agreed medication safety plan to prevent medication overdose. Resources and services—providing active advocacy and liaison with medical professionals, lawyers and Child Safety. Advocating on behalf of Sally for additional funding from Disability Services to support her to access therapy.
Implementation	<ul style="list-style-type: none"> Key worker provided long-term assertive outreach using creative modalities to support engagement to establish plans and resources for self-care and positive behaviour support. Crisis intervention—self-harm, drug use, suicide attempts, major incidents with family of origin, homelessness (sleeping rough), emotional issues and emergency after hours support. Providing supervision to volunteers, students and support workers. Early and frequent engagement with legal services to prevent Sally from entering the criminal justice system. Counselling and coaching to help Sally recognise and understand the complex pattern of relationship with her family of origin and educating about self-care strategies. New supportive relationships and networks – creating opportunities for new experiences and relationships by recruiting volunteers, support workers and students. Organising celebrations with Sally and her support network and contextualising each person's role in helping Sally belong. Advocacy, co-ordination and collaboration with the Department of Child Safety, Disability Services and other service providers. Access to mainstream services—building their capacity to understand and respond positively to Sally's legal, medical and counselling requirements.
Outcomes	<ul style="list-style-type: none"> Sally actively engages with ARROS workers and participates in ARROS peer events on a regular basis. Positive life vision and goals - Sally has moved from wanting to be a gangster

drug dealer to wanting to have a job, to maintain her housing, to see her niece and to be a good parent. She also wants to have a good relationship with her mother.

- Sally is developing a clear understanding of the (exploitative) patterns of engagement from her family of origin and is moving to a point where she is able to undertake some protective action in some situations.
- Supportive relationships—Sally has developed and maintained a long-term supportive relationship with a volunteer and a support worker and has included her best friend in planning sessions for support.
- Social participation—Sally is actively engaged in a music and youth project, which helps other young people leaving the care of the State.
- Accommodation—obtained and sustained affordable and safe housing.
- Economic participation—attending Centrelink and job agency independently.
- Financial management—Sally is no longer in debt with Cash Converters.
- Accessing services—regular supported visits to medical and legal services.
- Self-management (behaviour support plan)—increased capacity to regulate her emotions resulting in significantly decreased self-harm behaviour, and a mutually agreed medication safety plan to reduce the risk of medication overdose.

Conclusion

- ARROS provided proactive outreach to engage with this young person to identify her support needs. This resulted in access to support services she would not have received previously. Sally now has a real opportunity to redirect her life away from the trajectory of incarceration.
- To achieve this required many hours to slowly establish relationships including the use of creative methods for engagement and flexibility to reschedule appointments when she presented drug affected, without judging. It also meant having the flexibility to respond to crises out of hours.
- This work is gently persisting with Sally to articulate and align her goals as she matures and gains confidence from her newfound stability in life.
- Working to strengthen close relationships requires dedicating time to include special people as well as building connections to new supportive relationships and services.
- A significant amount of outreach time is channelled into relationship maintenance with Sally – having fun, being creative, hanging out. This has given us the platform from which we can provide substantial challenges, and then follow them up with significant support to help Sally meet the challenges we give.
- Sally had faced an interminable string of court dates, resulting from an accumulation of petty and criminal offences. After many years of constantly facing further charges, there was a window in her life where there were no outstanding charges, probationary periods or court dates.
- Sally told her ARROS worker that one of the good things about ARROS is “ARROS doesn’t break families up”, as opposed to other services, where she felt that she was being told not to keep seeing her mum because of the level of strain it put her under.

"I have no more court days now!"

"ARROS doesn't break families up" - Sally

"I'm going to live off the grid, so Energex feels the pinch!"

Expressing the realisation of his dream to develop a project where he could be self-reliant in energy generation.

NDIA Intellectual Disability Reference Group Topic Focus:

- Promoting equity of access to NDIS
- Planning and implementing support where participants lack effective informal support
- Decision making and participants with cognitive impairment
- Participants with complex behaviour
- Creating a positive vision for people with an intellectual disability

Practice focus:

- Pro-active outreach
- Skilled workers to build and hold a relationship with the young person
- Flexibility
- A commitment and ability to engage with the people in the young person's life
- Capacity to respond holistically

Referral: Jack is a 40 year old a man with Asperger's syndrome, depression and social anxiety disorder, who often displays very challenging behaviour in stressful situations. When he was referred to ARROS in 2005, he was very isolated and the centre of extreme neighbourhood conflict. Jack rejected the idea of having a disability and he found it difficult to name his needs. He lacked the effective informal support or advocates to plan and implement the support he needed to function within the community.

- Risk Factors:**
- Mental health deterioration and increasingly maladaptive behaviour impacting on his capacity to live safely (for himself and others) within community.
 - Social isolation from family and difficulty in making and maintaining supportive relationships.
 - Homelessness—behaviour and safety issues.
 - Negative involvement with Criminal Justice System (aggressive behaviour from and towards community members, property damage, arson).
 - Health deterioration —poor self-care (diet, hygiene, dental care, wound care).

- Engagement**
- Engaged with Jack to build relationship of trust to support a positive vision for his life and the capacity to manage his mental health and anxiety and develop supportive relationships.
 - Engaged with significant family members to re-engage following critical incidents.
 - Engaged with significant community members and service providers to advocate for Jack.
 - Engaged with community to support them to build their capacity to understand Jack and learn better responses to him to create positive relationships, including:
 - local police officers;
 - neighbours ;
 - health providers, e.g. GP, Psychologist, Psychiatrist, Dentist;
 - Department Housing Service officers;
 - Certain local businesses.
 - Responding to verbal and physical aggression towards workers.

- Planning**
- Close relationship and friendship —to develop supportive relationships, role models and people to visit.
 - Physical safety—mental health, intimate relationship, family relationships.
 - Support in decision-making—being realistic, money management, good health and hygiene, house cleaning (and hoarding).
 - To support community to understand and learn better ways to respond to Jack.
 - To explore work possibilities for Jack (e.g. worm juice micro business, lawn mowing).

- Implementation** Key worker provided:
- Positive active behaviour support to manage his emotions and responses.
 - Assertive proactive outreach.
 - Crisis intervention.
 - Supervision of volunteers and support workers.
 - Access to resources to address housing, economic participation and financial management goals.
 - Community capacity building to increase mainstream services and community members' capacity to understand Jack and respond positively.
 - Support to establish and affirm informal supports including having celebrations with his support network to acknowledge Jack's milestones and build positive vision.
 - Encouragement of Jack's skills and energy in work / business roles and personal creative pastimes.

- Outcomes**
- Jack has engaged with and sustained a trusting relationship with ARROS and from that safe base has made positive connections and relationships with key community people that provide effective informal support.
 - Jack has made substantive and positive life changes. He has increased capacity to manage his mental health (less reactive, less aggressive and less frequent episodes) leading to less frequent critical incidents (especially around lighting fires). He is proactively reaching out for support when his mental health deteriorates which enables ARROS worker and other service providers to intervene in situations to avert crises. There is less risk of harm to self and others.
 - Self care—increased interest in self-care and hygiene.
 - Stable accommodation—successful move from one DOH property to another (averting homelessness) and has maintained stable housing for several years.
 - Social participation—ongoing supportive relationships with local people including a team of local Police Officers and workers at local businesses who celebrate with Jack, e.g. a well attended birthday party every year. Jack is demonstrating increased ability to participate in events where there are large numbers of people present, including a trip to the Ekka this year.
 - Economic participation—ongoing employment over several years with: garden maintenance business; micro business supplying local coffee shops, and generating income (herbs, worm juice and vegetables).
 - Money management—Jack has shifted from being in debt to paying his bills, in advance, and having savings.
 - Jack is expressing his creativity through his pastimes – an off-grid tree house on a local farmer's property.

Conclusion

- Jack is part of a group of people who are at risk of missing out on NDIS support, because they reject the idea of having a disability and find it difficult to name their needs. This group lack effective informal support or advocates to plan and implement the support they need to function in the community.
- ARROS provided proactive outreach to a person with complex behaviour who is difficult to engage and who would not have easily negotiated an intake assessment process.
- To achieve this required many hours to establish a relationship including constantly fluctuating hours to work on goals, issues and to respond to crises.
- This work required skilled and well-supported workers who had the flexibility to engage in behaviour support, outside a clinical setting, as well as to build community relationships and social and economic participation opportunities.

"I'm going to live off the grid, so Energex feels the pinch!"

- Jack

RESPONDING TO THIS GROUP UNDER NDIS

The NDIS offers increased choice and control for people with a disability, including what support they access, and how and by whom it is delivered. It provides a great opportunity for people to increase their social and economic participation to enhance connectedness and contribution to society – in short, to have an opportunity for a good, or ordinary, life. Access to the benefits of NDIS may favour those whose needs are stable, quantifiable, well-articulated and able to be responded to with discreet quantifiable responses rather than those who are transient, whose needs remain unarticulated or expressed differently, who lack informal supports to represent them, and who are chronically disengaged.

The National Disability Insurance Agency (NDIA) - Independent Advisory Council (IAC) has set up the Intellectual Disability Reference Group to support them to consider what services and supports people with intellectual disability are going to need and how they could be delivered. The reference group is addressing the key question: What should the NDIA understand about intellectual disability? It has also identified a number of topics for the NDIA to consider in formulating its response to people with intellectual disability including:

- promoting equity of access to the NDIS
- the definition of intellectual disability
- planning and implementing support where participants lack effective informal support
- decision-making and participants with cognitive impairment
- participants with complex behaviour
- creating a positive vision for participants with intellectual disability
- information, linkages and capacity building
- participants in large residential centres
- parents who have an intellectual disability

The case studies in this booklet address a number of these topics and highlight the very real possibility of people relegated to society's fringe once again missing out. It is worth noting that whilst every person in the case studies should be considered eligible for NDIS support, not one of them could successfully access the NDIS as the intake process currently stands, without committed support over a long period.

Each of these stories is a powerful and compelling real life example detailing the circumstances that hold people in the margins. These are just some examples of why people with intellectual disability on the fringe may find the NDIS difficult to access. They highlight the challenges of dealing with extreme distrust of services and poor understanding of disability (and lack of diagnoses in many cases), alongside experiences of homelessness, poor communication, lack of informal supports and champions to advocate for them, poor mental health, high contact with criminal justice systems, and transient and chaotic lifestyles.

We hope our observations are useful to the NDIA in determining how to respond to those with intellectual and cognitive disability who are on society's fringe, and to other services, which may be able to tailor their own response to this group of people with a higher degree of understanding and responsiveness.

ARROS and CLA Inc. would like to acknowledge the contribution of the seven individuals who have agreed to share their stories here with you. Thank you for your courage in allowing us into your lives, and your leadership in highlighting the issues faced by people with intellectual disability living on society's fringe.

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