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The need for a community-led, holistic service response to Aboriginal young people with cognitive disability in remote areas: a case study

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Article

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Abstract

There are multiple structural and practical barriers to Aboriginal young people with cognitive disability in remote areas receiving the support and services they need. Multidisciplinary mixed-methods research over the past decade has provided evidence of the ways that many such young people end up with complex support needs and being 'managed' by police and justice agencies in the absence of appropriate early intervention, transition support and community-based options. This article presents and synthesises knowledge generated by this body of work and contextualises it within the experiences and trajectory of a young Aboriginal woman with cognitive disability and complex support needs from a remote town. This case study is drawn from a New South Wales linked administrative dataset containing data from health, housing, disability, human services, police, legal, court and justice agencies on a cohort of people who have been incarcerated. The article draws out key principles and strategies to suggest what a community-led, holistic service response could have looked like for Casey.

Introduction

Recent research has provided evidence of the multiple structural and practical barriers to Aboriginal young people with cognitive disability in remote areas receiving the services and support they need. These include distance from specialist services and professionals, entrenched social and economic disadvantage, lack of access to positive educational, recreational and employment opportunities and pathways and the legacy of colonisation, institutional racism and intergenerational trauma (Avery, 2018; Baldry et al., 2015; Dew et al., 2019; Ellem et al., 2019). There is a severe and widespread lack of appropriate early diagnosis and positive culturally responsive support for Aboriginal and Torres Strait Islander children and adults with cognitive disability. This is due, in part, to schools and police viewing certain kinds of behaviour through prisms of institutional racism and offending rather than disability (Baldry et al., 2015). Many Aboriginal young people with cognitive disability in remote communities experience compounding support needs which escalate in complexity; often because they are 'managed' by the criminal justice system in the absence of appropriate early intervention, transition support and community-based options (Baldry, et al., 2015; Dowse et al., 2014). The social and economic costs of this are extensive (Baldry et al., 2012). There is evidence that the early teenage years are frequently a critical time for disengagement from school and family, associated with a rise in contact with police, justice agencies and community services (Baldry et al., 2013; Baldry et al., 2015; Baldry & Dowse, 2013; Dowse et al., 2014; Smith & Dowse, 2019). Aboriginal young people with cognitive disability in remote areas are particularly disadvantaged by a lack of specialist information, services and support (Baldry et al., 2015).

This article reflects on the knowledge generated by research around the importance of early intervention, transition support and community-based options and pathways, contextualised in the experiences and trajectory of 'Casey', a young Aboriginal woman with an intellectual disability from a remote town. This case study is of a real individual drawn from a New South Wales linked administrative dataset containing data from health, housing, disability, human services, police, legal, court and justice agencies on a cohort of people who have been incarcerated (Baldry et al., 2012). Casey began a period of intensive police contact from the age of 12. She experienced unmet mental health needs, drug and alcohol use, multiple placements in out of home care, regular restraint and admission to the hospital under mental health legislation and cycling in and out of the criminal justice system with increasing frequency and punitiveness. The data each agency recorded about Casey was used to cost her institutional contact from the ages of 12 to 21, revealing the extraordinary costs that can be associated with the unsupported pathway of one young Aboriginal person with cognitive disability in a remote community (Baldry et al., 2012). This article then draws out key principles and strategies from the research reviewed to suggest what a community-led, holistic service response could have looked like for Casey. We focus on a single case study and so caution should be exercised in generalising these principles and strategies. However, we argue that the significant strengths in Aboriginal community-controlled organisations in remote towns, along with the emerging evidence about models of effective support and services for people with complex support needs, could be explored further in the development of more effective policy and practice responses.

Recent research

In this section, we set out the methodologies and findings of a number of recent multidisciplinary mixed-methods research studies that have contributed to knowledge around the ways that the absence of appropriate community-based support options for Aboriginal young people with cognitive disability in remote areas exacerbates the complexity of their support needs and results in default 'management' by police and justice agencies. This includes studies on improving transition support for young people with complex support needs, Aboriginal people with mental and cognitive disability in the criminal justice system, research collaboration with community-controlled organisations in the remote town of Walgett in north-west New South Wales and improving support planning in the National Disability Insurance Scheme for Aboriginal and Torres Strait Islander people with disability. All projects received ethical approval from institutional Human Research Ethics committees and the Aboriginal Health and Medical Research Council, where appropriate.

Supporting transitions for young people with complex support needs

The *Lost in Transition: Supporting young people with complex support needs*[1] project sought to identify the variety of ways in which transitions between services, institutions and care environments for young people with complex support needs can be better understood and supported. The project addressed how transition support is perceived by service providers (Ellem et al., 2019, 2020) and how transition is experienced by young people with complex support needs (Smith & Dowse, 2019). This project involved a range of qualitative and quantitative sub-studies utilising documentary analysis of key policies across multiple social care domains, statistical analysis of linked national minimum and bespoke datasets and qualitative analysis of focus groups and interviews with service providers and arts-based methods with young people with complex support needs. The project explored different kinds of transition experienced by young people, including moving from youth to adulthood, through education to work, or between services and systems. Together these studies showed that there are incongruent understandings of transition articulated in multiple policy domains and poor capture of transition within and between service sectors in national datasets. Understandings of transition revealed in policy and by service providers in practice were found to be largely focused on developmental or spatial transition such as leaving school, care settings or detention, whereas, for young people with complex needs, transition was associated with identity and belonging.

Using administrative data to calculate economic costs of criminal justice management of people with mental and cognitive disability

The *Mental Health Disorders and Cognitive Disability* (MHDCD) Databank,[2] a University of NSW longitudinal linked dataset containing administrative information from human service and criminal justice agencies for a cohort of 2,731 persons who have been in prison in NSW and whose diagnoses of mental and cognitive disability are known, has been used for multiple research studies over the past decade (Baldry et al., 2012, 2013, 2015). Men make up 89% of the cohort and women 11%. A quarter of the total cohort identified as Aboriginal or Torres Strait Islander persons. The MHDCD Databank researchers collected and linked data relating to these individuals via the creation of a relational database using Microsoft Structured Query Language (MS-SQL) server 2008. Extant administrative data were drawn from Police, Corrections, Justice Health, Courts, Juvenile Justice, Legal Aid, Disability, Housing, Health and Child Protection on each individual in the cohort from as far back as each agency's electronic records allowed (generally from around the mid-1980s) up to the date of data extraction between 2008 and 2012. Data on each individual was extracted from every agency they had been involved with and matched data for each person were added to the dataset as an agency-specific subset. Once linked and merged, individual identifying details were removed from the data. This enabled deidentified data to be extracted and analysed for research purposes, subject to strict ethics protocols in order to protect the privacy of those in the cohort. The dataset allowed for the development of innovative deidentified life course pathway case studies, as well as aggregated subset pathways and patterns of effects of agency interactions with individuals, subgroups and other agencies (Baldry et al., 2012, 2013, 2015).

One innovative use of the MHDCD Databank has been for economic analyses, in particular, the development of institutional costs for individuals drawn from the cohort. Cohort data was examined for all interactions with criminal justice and human services agencies and all services or interventions for which unit costs could be developed, such as police incidents, health events and hospital attendance, court appearances and custodial episodes. Estimates for all tangible costs allowed for by the data were developed, including direct costs (those that can be directly attributed to a service or intervention), indirect costs (those not directly attributable but necessary to the delivery of the service or intervention, i.e., management and administration costs) and capital costs where possible. Multiple studies using this method have been published in the past 8 years (Baldry et al., 2012; McCausland et al., 2013; McCausland et al. forthcoming; McCausland et al., 2019; Reeve et al., 2017; Reeve & McCausland, 2019). These economic analyses have highlighted ways in which the lack of adequate support services early in life is associated with increasingly costly criminal justice interactions, providing evidence that inadequate system responses contribute to and exacerbate complex support needs amongst socio-economically disadvantaged persons with mental and cognitive disability (Baldry et al., 2012; McCausland et al., forthcoming).

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[1] Australian Research Council Linkage Grant (Project LP150100528), UNSW 'Lost in Transition: Supporting young people with complex support needs'. Chief Investigators: Leanne Dowse, Philip Mendes, Iva Strnadová, Jung-Sook Lee, Therese Cumming, Pamela Snow, Louisa Smith and Kathy Ellem. Partner Organisations: Jesuit Social Services, Community Living Association Inc., NSW Department of Family and Community Services, Ageing, Disability and Home Care, Berry Street Victoria, Life Without Barriers.

[2] ARC Linkage Grant (Project LP0669246), UNSW, 'People with mental health disorders and cognitive disability in the criminal justice system in NSW'. Chief Investigators: Eileen Baldry, Leanne Dowse, Ian Webster; Partner Investigators: Tony Butler, Simon Eyland and Jim Simpson. Partner Organisations: Corrective Services NSW, Housing NSW, Justice Health NSW, Juvenile Justice NSW and the NSW Council on Intellectual Disability.

Aboriginal people with mental and cognitive disability in the criminal justice system

The *Indigenous Australians with Mental Health Disorders and Cognitive Disability in the Criminal Justice System (IAMHDCD) Project*[3] is a mixed-method study conducted by a team of Aboriginal and non-Aboriginal researchers. Quantitative analysis of the Indigenous cohort of the MHDCD Databank (see above) was combined with a qualitative component. This qualitative study involved the researchers partnering with Aboriginal community-controlled organisations in New South Wales and the Northern Territory to investigate the experiences and perspectives of Aboriginal people with disability who have been incarcerated, as well as service providers, family and community members (Baldry et al., 2015) The study approach was informed by critical disability and critical criminology theory that frames the overrepresentation and poor outcomes of people with cognitive disability in criminal justice systems as the result of systemic discrimination and policy failure (Baldry et al., 2015). The IAMHDCD Project traced the ways that, from a young age, Aboriginal people with disabilities from disadvantaged backgrounds are forced into the criminal justice system in the absence of holistic human services, disability and educational support. The study highlighted the ways that Aboriginal people with complex support needs experience multiple, interlocking and compounding disadvantageous circumstances and revealed that these experiences are overwhelmingly characterised by complex trauma related to disadvantage, racism, marginalisation and harm. The study provided quantitative and qualitative evidence of the ways in which the pathways into the criminal justice system for Aboriginal people with mental and cognitive disability are embedded and entrenched by default due to a lack of appropriate diagnosis, early intervention and positive, culturally responsive support (Baldry et al., 2015).

Recommendations developed from the research with community-controlled collaborators included the following principles and strategies to underpin reform and to ensure that the criminal justice system is no longer the default institutional response to Aboriginal people with mental and cognitive disability (Baldry et al., 2015). *Principle 1: Self-Determination* is key to improving access to and exercise of human rights and to the well-being of Indigenous people with mental and cognitive disability, especially for those in the criminal justice system. Strategies included that Indigenous-led knowledge and solutions and community-based services should be appropriately supported and resourced, and the particular disadvantage faced by Indigenous women and those in regional and remote areas should be foregrounded in any policy response. *Principle 2: Person-Centred Care* which is culturally and circumstantially appropriate should be adopted, placing an individual at the centre of their own care in identifying and making decisions about their needs. Strategies included that specialised accommodation and treatment options for Indigenous people with mental and cognitive disability should be available in the community to prevent incarceration and in custodial settings to improve well-being. *Principle 3: Holistic and Flexible Approach* can be used in the provision of services to allow Indigenous children and young people with disability to develop and flourish. Strategies included early recognition via health services, education and police staff with the aim of supporting positive and preventive therapeutic support. *Principle 4: Integrated Services* to improve referral, information sharing and case management to better support Indigenous people with mental and cognitive disability in the criminal justice system. *Principle 5: Culture, Disability and Gender-informed practice* are vital including that Indigenous understandings of 'disability' and 'impairment' inform the development and implementation of policy and practice, with particular consideration of issues facing Indigenous women. Strategies included better education and information for police, teachers, lawyers, magistrates, health, disability and community service providers regarding understanding and working with Indigenous women and men with disability and complex support needs, and that information and resources are needed for Indigenous communities, families and carers, provided in a culturally informed and accessible way (Baldry et al., 2015).

Research collaboration with Aboriginal community-controlled organisations in Walgett

One of the communities involved in the IAMHDCD project was Walgett, a remote town in far north-west NSW. Walgett has been measured over decades as one of the most disadvantaged locations in Australia, yet also has great strengths in its local Aboriginal community-controlled organisations and engagement in research and advocacy (McCausland et al., forthcoming). Community-controlled organisations that were part of the IAMHDCD Project included Walgett Aboriginal Medical Service (WAMS) and Dharriwaa Elders Group (DEG). WAMS is an Aboriginal community-controlled health service that provides a GP clinic, preventative health screening, chronic disease management, dental, family health, sexual health, antenatal and postnatal care, mental health support, drug and alcohol counselling and allied health services (WAMS, 2020). The Dharriwaa Elders Group (DEG) is an association of Aboriginal Elders who provide leadership on a range of community development and engagement activities to pass on cultural knowledge and improve education, employment, health and life prospects for the Aboriginal community in Walgett (DEG, 2020). In Walgett, Aboriginal researchers from the IAMHDCD Project heard from people with mental health disorders and/or cognitive disability who had been in the criminal justice system, family and community members and service providers from the community-controlled, government and non-government sectors including health, disability and justice, and those interviewees contributed to the project's findings and recommendations (Baldry et al., 2015).

When UNSW researchers were reporting back on the findings and recommendations of the IAMHDCD Project in 2015, DEG and WAMS invited the researchers to participate in a facilitated whole of community discussion about what was needed to respond locally to the issues raised in the research. In the years since, at the invitation of the DEG, a formal partnership has been developed between the DEG and UNSW that aims for long-term systemic change in Walgett (McCausland et al., forthcoming). 'Yuwaya Ngarra-li' is a community-led partnership focused on improving the well-being, social, physical and built environment and life pathways of Aboriginal people in Walgett through collaborating on evidence-based initiatives, research and capacity building. Through Yuwaya Ngarra-li, the partnership is developing and testing a new model of 'CommUNIty-Led Development' which centres the needs and priorities of Aboriginal people through the leadership of a respected local community-controlled organisation and is underpinned by research and evaluation

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[3] Australian Research Council Linkage Grant (Project LP100200096), UNSW, 'Indigenous Australians with mental health and cognitive disability in the criminal justice system in NSW'. Chief Investigators: Eileen Baldry, Leanne Dowse, Julian Trollor, Patrick Dodson. Partner Organisations: Justice Health, Housing NSW, Ageing Disability and Home Care NSW, Legal Aid NSW.

(McCausland et al., forthcoming). WAMS remains a key collaborator in Yuwaya Ngarra-li, especially on projects that focus on social and emotional well-being, water and food security and child injury prevention (McCausland et al., forthcoming).

Early on in the work of the partnership, the DEG identified as an urgent priority the problem of young Aboriginal people in Walgett being disengaged and suspended from high school and at great risk of contact with the criminal justice system, particularly those young people with cognitive disability and/or behavioural disorders (McCausland, 2018). The lack of local culturally appropriate, holistic support and pathways into education and employment for young people was seen as a significant problem associated with the high levels of unmet needs relating to disability, mental health and drug and alcohol use. Local court data revealed that in 2016, 56% of Aboriginal young people aged 15–17 living in Walgett appeared in the local children's court (McCausland, 2018). A Walgett Youth Justice Forum convened by Yuwaya Ngarra-li in 2018 enabled community voices and concerns, including those of young people themselves, to be heard alongside that of researchers, police, lawyers, health, education and community-controlled services. The DEG was clear that the forum should be immediately followed by an implementation plan to ensure that clear undertakings to the community were made for action (McCausland, 2018). The Walgett Action Plan for Children and Young People was launched 3 months later. The focus is on building relationships of respect and developing effective coordination and collaboration between relevant people and organisations within Walgett; with the aim of significantly improving education, training and employment participation and outcomes and creating effective options for the diversion of children and young people from the criminal justice system, including those with cognitive disability (Yuwaya Ngarra-li, 2018).

Improving support planning for Aboriginal and Torres Strait Islander people with disability

The appropriateness and effectiveness of the individualised approach to support planning for Aboriginal people with disability has been of significant concern since the introduction of the NDIS. Building on the Yuwaya Ngarra-li partnership, a scoping study to identify the key issues that must underpin a safe and sustainable disability plan for Aboriginal people with disability and complex support needs and their informal supporters were undertaken with the Walgett community (Dew & McEntyre, 2017). This study involved qualitative research with Elders with lived experience as carers of family members with disabilities. The Elders identified seven crucial foundations that highlighted that for them, addressing what might be constructed as individual needs have cultural, collective, spatial and systemic dimensions. First, the *centrality of culture*, described as 'encapsulating spirituality, ancestors, land, family and community and physical wellbeing . . . which are interlinked and any planning discussions with Aboriginal people must have a primary focus on the importance of culture' (Dew & McEntyre, 2017, p. 3) is important for Aboriginal people in Walgett. A *holistic and long-term approach* to planning is needed based on how the person views themselves and is viewed by others, including their family and community connections. *Intergenerational issues* to consider in planning include the trauma, loss, grief, violence, chronic illness and disadvantage and associated shame that may be experienced by Aboriginal people with disability and their carers. The *impact of geographic location* means that the different needs and experiences of Aboriginal people with disabilities living in a remote community need to be taken into account, including travel costs to access specialist services and supports. *Access to information about services and supports* can be a barrier, and Aboriginal people may be more comfortable asking for help from locally-based services including AMS workers with whom they already have a relationship. The lack of *locally available services understanding disability*, including those with specialist staff to diagnose and support people with disabilities was identified as a significant impediment. A preferred model of support and care instead should recruit, train and support Aboriginal people living in the community to ensure their retention in direct disability service roles within the community (Dew & McEntyre, 2017).

Building on this scoping study, Dew et al. (2019) developed a framework to better prepare organisations to plan with Aboriginal and Torres Strait Islander people with disabilities under the NDIS. '*Our Ways to Planning*' was grounded in research that indicated Aboriginal and Torres Strait Islander people experience disability at twice the rate of non-Indigenous people and face complex issues associated with co-occurring physical and psychosocial ill-health along with discrimination and intersectional inequality, but are less likely to access services and supports (Avery, 2018; Biddle et al., 2012, Gilroy et al., 2018, Phuong 2017 in Dew et al., 2019). Aboriginal people who do engage with formal services often experience barriers to receiving the full range of possible supports in ways that work for them (Gilroy et al., 2018). To be eligible for NDIS funding, a person must show she or he has permanent functional impairments resulting from a disability that significantly affects his or her life and is ongoing. Once identified as eligible for individualised NDIS funding, a person with disabilities, in conjunction with an NDIS-approved planner, must make a plan specifying short- and long-term goals and identifying the supports and services needed to achieve these. In reporting on this framework designed to better prepare organisations to plan with Aboriginal people with disability, Dew et al. (2019) identified that Aboriginal people who do engage with formal services often experience barriers to receiving the full range of possible supports under the NDIS. One major hurdle is in relation to identifying goals and making person-centred plans as an individualised approach, which is incompatible with the collectivist worldview held by many Aboriginal people, in which identity is inextricably bound with extended family ties, community and culture, and are identified as central to social and emotional well-being for Aboriginal people (Avery, 2018; Dew et al., 2019; Stewart & Allan, 2012). This means that planning with an Aboriginal person with disabilities must have a family, community and culture focus and be based on how the person views him or herself as well as how they are viewed by others, including family, community and broader social and cultural connections (Dew et al., 2019). The framework draws on the First Peoples Disability Network Australia (FPDN) 10-point plan for implementation of the NDIS with Aboriginal and Torres Strait Islander people with disability, including three pillars to address disability inequality (FPDN, 2018): *1. Build the capacity of communities and individuals to understand their rights and entitlements. 2. Invest to create a First People's Community-Controlled service sector. 3. Develop and support an Aboriginal and Torres Strait Islander workforce* (FPDN, 2018, in Dew et al., 2019).

The lived experience of systems failure

The body of research presented above, published over the past decade, has drawn on work with and informed by Aboriginal people with cognitive disability and those who provide support to them. Taken together, it articulates a breadth of considerations that are understood to contribute to not simply a lack of capacity to appropriately identify and respond to the support needs of Aboriginal people with disability, but rather a web of causative and systemic factors and conditions which actively work to create and exacerbate intersectional disadvantage for Aboriginal young people with cognitive disability. Over this period, efforts to address incarceration and services for young people with cognitive disability and complex support needs have seen some success, for example, the overall reduction in numbers of young people in detention in NSW youth justice settings, but this has, on the whole, not extended to Aboriginal young people where the enduring trend of over-representation continues (Justice Health & Forensic Mental Health Network and Juvenile Justice NSW, 2017). In this complex context, we are also mindful that arguments for systemic reform specific to the issues for Aboriginal young people with cognitive disability must at all times be informed by the lived experience of such young people and their families and communities. To this end, we present below a case study compiled from the MHDCD Databank of one young Aboriginal woman from a remote community: 'Casey'. Taken from the report by Baldry et al. (2012, pp. 90–92), Casey's institutional pathways and interactions from the ages of 12 to 21 highlight the significant social and economic costs of failed system responses. We emphasise that this story is drawn from administrative records about 'Casey' and does not capture Casey's voice or her perceptions and reactions to her experiences. Nonetheless, we argue that understanding the scale and detail of institutional contacts and responses and their perverse interaction in Casey's life provides an important lens on the lived experience of cognitive disability for Aboriginal young people in remote areas.

Casey

> *'Casey' is a young Aboriginal woman, born in 1989, who has been diagnosed with a range of mental and cognitive conditions, including behavioural and emotional conditions emerging in childhood and adolescence. These include ADHD, Conduct Disorders, Adjustment Disorders and Personality Disorder. These diagnoses are maintained as she enters adulthood with an additional diagnosis of Bipolar Affective Disorder made at age 17. Casey has also been identified as having a developmental delay and intellectual disability. She has been assessed as having an IQ score of 64 (Verbal IQ 66, Non-verbal IQ 68) placing her in the intellectual disability range. She has a long history of self-harm, physical abuse and trauma. As a young adult Casey is identified as experiencing recurrent depressive disorder, is obese and suffering from asthma. Corrective Services notes indicate alcohol abuse from a young age and other indicators of a drug problem. After the age of 13 Casey barely attends school.*
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> *From the age of twelve Casey begins a long and intensive pattern of contact with criminal justice and human service agencies beginning with a notification by her mother of concerns for her child who is 'walking the streets' of her remote NSW town at night. Her first Police contact occurs at this age as a result of this notification, in which Police note that she is threatening suicide and is 'highly agitated and suffering from a mental illness'. Casey is conveyed to the local hospital by an ambulance where, due to her distress, she is restrained by police and medical staff and sedated. [Community Services] are notified. Soon after, Casey begins a pattern of repeated 'nuisance calls to 000', resulting in Police attending. In some instances Casey is observed to be distressed or irrational. As a result she is admitted to hospital under the Mental Health Act on multiple occasions where she is usually sedated and restrained and released the following morning. On several occasions in her teenage years Casey is refused admission to the hospital with police and doctors concurring that 'the young person just enjoyed the attention her behaviour generated'. Police records indicate that a range of community, mental health, education and other agencies attempt to develop a plan to 'deal with her' but 'difficulties lie with the fact that there is little or no facilities in the state to deal with a young child with this behavioural problem'.*
>
> *As a young person Casey has very frequent interaction with police. For instance when she is 13, she is the subject of 87 Police events, as a result of which she is taken into police custody 35 times and charged on 56 different counts. Often, Casey is violent and resists police intervention and is restrained. Police also note frequent threats and attempts at self-harm when she is taken into custody. On numerous occasions services fail to support Casey. For example, workers from a local mental health service will no longer have Casey released from Police into their custody, and child protection services inform the Police 'they have nowhere to place the child' and 'refuse to have her in their custody'. As a result, Casey's mother is the sole support person, and on numerous occasions indicates that she is 'unable to control the child and is not prepared to sign a bail agreement'. Since the hospital is also no longer prepared to admit Casey, 'there is no other option available to police than to house the child'. In one incident at her family home when she is 13, Casey's mother contacts Police to request assistance 'because she can't control her' daughter who is damaging property in the house with a pair of scissors. Casey's mother indicated to Police that 'she did not want her daughter charged, she just wanted support. She states that 'child protection services wouldn't help her and the only thing she could do was ring the Police'.*
>
> *As Casey moves into her middle teen years, as a result of her frequent offending Casey also has multiple juvenile custody episodes. She is frequently suspended and ultimately expelled from school when she is 15 and continues to be scheduled under the Mental Health Act and admitted to both the local hospital and regional psychiatric hospital. Police note their concern that 'this child is in need of medical and mental treatment. She is being bounced around between Police and the Hospital at least three times in the past two weeks'. They make multiple child protection reports as they hold fears 'that the young person may be physically, emotionally or psychologically abused'. When it becomes clear that the relationship between Casey and her mother has broken down, [Community Services] struggles to find Casey appropriate foster care. At this time Casey's bail conditions continue to require that she 'reside in her family home and not be absent between the hours of 6pm and 6am' creating a situation in which Casey will almost inevitably breach her bail conditions.*
>
> *When she is fourteen Casey is placed in temporary out-of-home residential care with a private service organisation which provides specialist support to young people at risk. During this period Casey frequently assaults her carers, damages property and absconds from her accommodation. Police note on one occasion that 'it appears the child is desperately home sick and has no family or friends down here'. Threats and attempts at self-harm during this time are noted to be escalating.*
>
> *At the age of seventeen Casey is transferred into a residential setting with a disability focus, where her pattern of frequent self harm, assaulting carers, damaging property, absconding from the facility and resisting arrest continues. She is admitted to hospital for overnight stays on three occasions and following this she is placed on a control order and serves a further two months in a juvenile detention centre where she attempts to set fire to the mattress in her cell. Police events throughout this year follow a similar pattern, with 41 events resulting in 29 charges. Casey continues to be admitted to juvenile detention, serving two months on a control order. Three other stays of short periods are as a result of being remanded by the court and Police charges.*
>
> *Casey completes her final stay in youth justice custody on her eighteenth birthday and returns to her residential placement. At this time a Guardianship order is granted whereby the Office of the Public Guardian assumes responsibility for Casey. In her residential placement, her patterns of self-harm and suicide attempts, absconding and offending continue, resulting in further psychiatric admissions. During one of these stays she is sexually assaulted.*
>
> *Aged eighteen, Casey serves time in adult corrections where she is placed in a specialist acute female unit where she maliciously damages the flooring of her cell and is restrained with a belt and handcuffs to prevent harm to herself and Correctional staff. On release she becomes a client of the Community Justice Program, an intensive 24 hour supported*

> *accommodation service which obviates her police and other criminal justice contacts for the first time in her life.*
> *(Baldry et al., 2012, pp. 90–92).*

The costs of Casey's institutional interactions, first developed in Baldry et al. (2012), have recently been updated (Reeve & McCausland, 2019) (Table 1).

Casey's intellectual disability appears to be a key factor precipitating her institutional contact. She is a client of multiple government agencies and community-based services from a young age, and yet due to her 'problematic behaviour', responsibility for responding to her significant and increasingly complex needs is consistently left to the police. These police costs alone are more than $700,000 before she turns 18. Casey's is a clear case of cost-shifting to the criminal justice system, until she becomes a client of the Community Justice Programme at the age of 18 (Baldry et al., 2012). This intensive program involving 24-hour support and accommodation is costly due to Casey's complex support needs by the age of 18. If a fraction of those funds had been invested earlier in her life to appropriately support her in her family and community, the social and economic costs associated with her trajectory may have been significantly less.

Discussion: what would it take to better support Casey?

Casey's experiences and trajectory highlight the way that a young person with cognitive disability can become entrenched in the criminal justice system. Without being provided appropriate support or services, they experience the pervasive and compounding impacts of institutional racism, social and economic disadvantage and remote location. Casey's intensive contact with government agencies beginning in her adolescence and continuing into early adulthood is characterised by inappropriate responses, unmet behavioural and mental health support needs and cost-shifting. Her multiple and simultaneous spatial, service and care transitions reveal a life of significant chaos and compounding harm.

While Casey was a client of community and disability services and a number of other community-based agencies from a young age, due to what was perceived as her 'problematic behaviour' and the incapacity of community agencies to meet her support needs, this behaviour was criminalised and police became the default managers of her care (Baldry & Dowse, 2013). This was extraordinarily costly in human and economic terms. For Casey, positive intervention was only available once she became an adult, but by that time she had become entrenched in the criminal justice system. The provision of intensive 24-hour supported accommodation and multiple case managers was costly, but ultimately effective in keeping Casey out of the criminal justice system for the first time since her high level of contact began as a young teenager. If even a fraction of these resources had been engaged earlier in Casey's life to support her, her mother and local staff in her community to respond to her needs, Casey's trajectory could have been significantly different.

The body of research set out in this article has generated knowledge at systemic, community and individual levels about how Casey's pathways and experiences could have been different. While Casey is one example of the failure of systems and services to adequately support a young Aboriginal person with cognitive disability in a remote community whose trajectory was particularly costly to the state, there are hundreds of young people in similar circumstances (Baldry et al., 2015; FPDN, 2018). Clearly, a more humane and effective service response is needed.

Integrating recent knowledge: a community-controlled, holistic service response

In considering how we may conceptualise a more positive institutional response to Casey, this section summarises five elements identified in the research outlined earlier in this article. We propose that attention to these may have created the foundations for a more community- and culturally-led and integrated multisystem response to Casey.

Holistic and flexible models of support

Services and programmes are often designed to address a specific need, such as homelessness or mental health, but do not cater for people with complex support needs – for example, an Aboriginal young person like Casey with cognitive disability who also has escalating unmet needs relating to her mental health and drug and alcohol use. A holistic and flexible approach adopted in the provision of services to Casey as early as possible could have assisted in avoiding engagement with multiple parallel agencies as well as early and ongoing contact with the criminal justice system. Specific attention to identifying and supporting key transitions between settings and services would obviate the need for recourse to default management by hospital emergency admission and police intervention. Research indicates that having local staff with appropriate training who are known, trusted and available to young people and their families in an ongoing capacity, and who are able to be responsive when needed could have made a significant positive difference in Casey's life.

Therapeutic, trauma-informed approach rather than punitive response

Aboriginal children and young people who may have cognitive impairment regularly face a punitive response, being perceived as poorly behaved rather than needing diagnosis and specialist support. Better understanding and resourcing around early recognition and diagnosis via child health services, school education, community health services and police staff for Casey ideally would have led to positive and preventive support, allowing her to develop and flourish in her own community. A trauma-informed approach that recognises the intergenerational legacy of the forcible removal of Aboriginal children from their families and communities could have assisted so as not to compound or further traumatise Casey, but instead support strengths and agency in addressing the trauma-related factors underlying her contact with the out of home care and criminal justice systems (Bamblett et al., 2014). If the initial approach to Casey had been trauma-informed, the harm of a punitive response focused on restraint and removal of Casey from her home town and family may have been considered, and an alternative local strengths-based approach to supporting her and her mother been possible.

Diversionary options at all stages of contact with the criminal justice system

Diversionary options specifically oriented for people with cognitive disability are rare, and where they do exist, tend to be available only to those appearing in courts in metropolitan or regional centres, or where specialist services are available to provide support. There are very limited formal diversionary options available in relation to Aboriginal young people like Casey who live in a remote area, coupled with a greater likelihood that police, lawyers, magistrates and other justice officials will not have access to specialist information, training or staff to enable them to respond appropriately to people with

Table 1. Casey's institutional costs over time

Agency	12–13 yrs	14–17 yrs	18–21 yrs	Total cost
Police	$ 202,683.84	$ 504,598.31	$ 50,670.96	**$ 757,953.11**
Out of home care	$ 11,069.00	$ 684,598.40		**$ 695,667.40**
Courts	$ 7,266.00	$ 15,208.72	$ 1,849.69	**$ 24,324.41**
Juvenile Justice	$ 225,379.43	$ 472,295.79		**$ 697,675.22**
Adult Corrections			$ 46,721.50	**$ 46,721.50**
Legal Aid	$6,740.00	$ 17,720.00	$ 380.00	**$ 24,840.00**
Health	$ 28,399.72	$ 382,742.08	$ 15,278.83	**$ 426,420.63**
Justice Health		$ -	$ 116,297.94	**$ 116,297.94**
Centrelink		$ 44,429.84	$ 48,907.39	**$ 93,337.23**
Community Justice Programme			$ 3,924,481.62	**$ 3,924,481.62**
Total	**$ 481,538**	**$ 2,121,593**	**$ 4,204,588**	**$ 6,807,719.09**

cognitive disability and complex support needs. Police documented their concerns about the poor institutional response to Casey's increasingly troubled behaviour but seemed unable to access alternative options or appropriate support. From the earliest contact with police, diversionary options for young people like Casey should be in place to assist in reducing her destructive and costly trajectory into the criminal justice system. There would have been a significant social and economic benefit to diversionary options designed and resourced to create genuine pathways out of the criminal justice system into services and support in the community for Casey at all points of interaction with the criminal justice system: police contact, cautioning, court, remand, custody and post-release from prison.

Disability, gender and culturally-informed policy and practice

Aboriginal and Torres Strait Islander people are more likely to experience disability and to end up in the criminal justice system than non-Indigenous Australians. The legacy of past and present experiences of discriminatory, controlling and exclusionary policies and practices, including the Stolen Generations, is significant. Aboriginal families may be reluctant to identify a child as requiring additional support or intervention due to fears regarding potential removal from family and community. There are disproportionate and compounding impacts of a lack of appropriate culturally-informed services and support on Aboriginal and Torres Strait Islander women with disabilities in particular. To be effective, any service response to Casey needed to be informed by Indigenous people's understandings of disability and impairment, the particular history, dynamics and cultural context of communities and geographic locations and the distinct and specific needs of Aboriginal and Torres Strait Islander women.

Aboriginal community-controlled services

Most Aboriginal people live in urban areas, but the majority of the population in remote areas are Aboriginal. Casey's first institutional contact is recorded after her mother calls the police in relation to her concerns about her daughter being out at night; the only after-hours 'service' resourced to respond in remote towns is usually the police, as it was for Casey. A potential alternative for providing local, culturally safe services to Casey would have been the local Aboriginal Community-Controlled Health Service – such as the Walgett Aboriginal Medical Service – that are common throughout rural and remote NSW areas but also in regional centres and urban areas. The Aboriginal community-controlled health sector delivers high quality, comprehensive and culturally-informed health care and is run for and by Aboriginal communities (Campbell et al., 2017), providing approximately 50% of all primary health care to Aboriginal and Torres Strait Islander peoples (Panaretto et al., 2014, 649–50). Such services are set up to provide culturally safe primary health care for Aboriginal people, and with appropriate resourcing and training, would have been ideally placed to coordinate a trauma-informed therapeutic response to Casey and her mother before her situation escalated to crisis, hospitalisation and incarceration. In reviewing the evidence on trauma-informed services for Aboriginal children, Atkinson (2013) identifies a number of programmes whose models could have equipped Casey's local Aboriginal community-controlled health organisation to provide the support she needed, including the 'Yarning Up on Trauma' education package to help workers understand the effects of trauma and support appropriate interventions for Aboriginal children; the therapeutic approach of Aboriginal child and family counselling service Yorgum; and the We Al-li Working With Children – Prevention and Healing course that is designed by, with and for Aboriginal practitioners. A positively evaluated programme that could have provided support to Casey and her family is the Aboriginal Family Wellbeing Program that focuses on social and emotional well-being needs to create supportive environments for children to thrive (Lowitja Institute, 2015). A further example of a programme model that could have been appropriate for Casey is that run by the Derby Aboriginal Health Service in remote Western Australia's Social and Emotional Wellbeing Team that provides trauma-informed clinical and cultural support with a specific programme focusing on girls at risk (NACCHO, 2020).

Broader lessons from this case study

Casey's experiences and trajectory are not unique. The conditions and circumstances that led to her intensive police contact from the age of 12 connected with an unmet disability and mental health needs and drug and alcohol use, her multiple placements in out of home care, her regular admission to hospital under mental health legislation and pattern of cycling in and out of the criminal justice system with increasing frequency are shared by hundreds of other young Indigenous people each year. Aboriginal and Torres Strait

Islander young people make up more than half of those in youth detention despite only making up to 3% of the population (AIHW, 2020), and Aboriginal young people in custody have very high rates of intellectual disability and mental health disorders (McCausland & Baldry, 2017). NSW data indicate that around a quarter of Indigenous young people in custody have a diagnosed intellectual disability and 65% are diagnosed with a mental health disorder (Justice Health and Forensic Mental Health Network and Juvenile Justice, 2016). A Western Australian study found that 89% of young people in custody, the majority of whom were Aboriginal, had some form of severe neurodevelopmental disability (Bower et al., 2018). Research indicates that there is a severe and widespread lack of appropriate early diagnosis and positive culturally responsive support for Aboriginal and Torres Strait Islander children and adults with cognitive disability, in part due to schools and police viewing certain kinds of behaviour through prisms of institutional racism and offending rather than disability, which can lead to exclusion from schools and increased contact with police (Baldry et al., 2015). Hundreds of Aboriginal young people with cognitive disability in remote communities experience compounding support needs which escalate in complexity, often because they are 'managed' by the criminal justice system in the absence of appropriate local early intervention, transition support and community-based options (Baldry et al., 2015; Dowse et al., 2014).

As this article has highlighted, the economic costs of regular and escalating contact with the criminal justice system for Casey are significant, and research involving other case studies and cohorts reflects that Aboriginal young people experiencing multiple disadvantages and diagnoses generally become more costly to the system over time (Baldry et al., 2012; McCausland et al., 2013). A cost–benefit analysis of providing early support and intervention for Casey concluded there could be savings of between $1.40 and $2.40 for each dollar invested in mental and cognitive disability-specific programmes (McCausland et al., 2013). The programmes of support and intervention included in that analysis were existing programmes that were not specifically tailored for Aboriginal young people and indeed are not even widely available in regional or remote areas. The five measures detailed here, if resourced, implemented and evaluated appropriately, could potentially improve the accessibility of more specialist support and services and the lives of young people like Casey.

Conclusion

Casey's experiences and trajectory highlight the way that a young person with cognitive disability can become entrenched in the criminal justice system without appropriate support or services given the pervasive and compounding impacts of institutional racism, social and economic disadvantage and remote location. Her intensive contact with government agencies beginning in her adolescence and continuing into early adulthood is characterised by inappropriate responses, unmet behavioural and mental health support needs and cost-shifting. Her multiple and simultaneous spatial, service and care transitions reveal a life of significant chaos and compounding harm. Data indicates that hundreds of Aboriginal young people with cognitive disability every year are being 'managed' by the criminal justice system in the absence of appropriate early intervention, transition support and community-based options. Understood through the detail of one young Aboriginal woman's early contact with human services and criminal justice agencies and subsequent trajectory and associated costs, the case for an alternative approach is apparent and compelling. The knowledge generated by recent studies outlined in this article suggests the elements of a community-led, holistic service response. Caution should be exercised in extrapolating to any systemic recommendations from a single case study, however, we propose that the significant strengths in Aboriginal community-controlled organisations combined with the emerging evidence about models of effective support and services offer great potential in the pursuit of more effective policy and practice responses to Aboriginal young people with cognitive disability in remote areas.

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