

The experiences and hopes of young people with intellectual and/or cognitive disability and transition from out of home care: Practice Issues and Responses informing Transition from Care practice and models.

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Summary

Young people with intellectual disability transitioning from out of home care are recognized as an extremely vulnerable / marginalized group of young people. They face significant barriers to successful transition from out of home care, which when not adequately addressed or responded to, places these young people at significantly higher risk of poor outcomes, both in the immediate and long-term trajectory of their lives. The intersection with homelessness, poor mental health, early parenting, unemployment, substance use, criminalization and social exclusion is significant. With improved access to appropriate support, it is hoped that these issues can be more effectively responded to, improving the outcomes for these young people.

This document captures young people's ideas on what it would take to support successful transition to adulthood. A case study highlights both the challenges this cohort face and the practice and systems responses required, to enable young people to live lives of meaning, where they feel safe, connected, and belong.

The paper is drawn from collaborative work with young people with their direct input. It recommends:

- 1. **Funding for services and support** utilising a service model that provides young people with support that is:
 - a. Built on relational practice that is young person centred
 - b. Flexible, adaptive, responsive, and engages in proactive outreach
 - c. Trauma informed and disability informed
 - d. Staffed by skilled **Social Work and Human Services (SWHS) professionals** with specialized skills across all areas of practice, to enable the navigation of complex systems and individual lived experience, alongside young people.
 - e. Allows for **flexibility with the age range** as due to their high levels of vulnerability, experiences of violence and exploitation and complex mental health experiences, successful transition from care can take longer than the current age range of 18-21.
- 2. **Housing first opportunities:** transitioning into housing that is safe and secure is necessary for young people to build their lives after care experiences. Housing that is appropriate enables safety and stability to create space for young people to build their capacity as emerging independent adults. Housing opportunities must be developed that are creative, flexible, and responsive options for the diverse needs of young people leaving care. Rather than a specific housing model, opportunities should include consideration for individual young people's needs such as matching people with tenancies, building relationships with co-tenants and neighbours, and availability of housing stock for those in need.

- 3. **Increased access to individual financial assistance** to be used flexibly by individual young people, to support their transition. For example, funding that may be used for housing sustainability, health care, psychological support, education.
- 4. Funding to develop practice models to ensure young women and men with intellectual disability have access to build their knowledge and understanding regarding their reproductive rights and to learn skills to build health and positive relationships, to ensure young peoples' journeys into parenthood are planned and they access and receive support appropriate to their situations and learning needs.

Purpose

This paper advocates for the consideration of the needs of young people in the child protection system, who have intellectual disability and are at risk of homelessness, regarding their support needs post transition from care, as currently, there are limited services and support within our community that can appropriately and effectively respond to this cohort. The intention is to do so through prioritizing the voices of young people, and their wisdom of what works and what does not, alongside the practice wisdom of the social workers who walk alongside them.

These young people face significant barriers and complexities within their lives resulting in mainstream services finding it difficult to engage; young people are often considered hard to reach and their needs are often not met as they fall through service gaps. This paper documents both the challenges facing young people with intellectual and/or developmental disabilities in out of home care and proposes program models and the practice it takes to ensure this cohort have access to appropriate and effective support during their journey through transition to adulthood. It is expected with funding to implement best practice models of support, young people will experience improved outcomes with a fighting chance of successfully transitioning through and beyond the child protection system, to lead lives that are filled with meaningful roles, including employment, connection and places to belong. To highlight these issues and the practice it takes to connect with young people to achieve their transition goals (safe house, safe relationships, engaged in community, parenting), the intention is to highlight both young people's perspectives alongside the ARROS practice knowledge, which has been developed through walking alongside the young people with whom we work. This document intends to ensure that these young people are not missed in the roll out of future supports and services.

ARROS (Community Living Association Inc)

ARROS was established in 1996 in response to the needs of young people with an intellectual disability experiencing, or at risk of homelessness, as it was observed through practice and subsequent research that this cohort was at significant risk and were falling through gaps within existing service provision due to the barriers they face. ARROS practice continues to evolve in response to this cohort through ongoing practice reflection and development, and working collaboratively with young people and their networks to understand the challenges they face, their needs, their goals, and their knowledge of what best supports them to enable them to experience successful transitions from care. The ARROS team of social work and human service practitioners continues to support young people with intellectual and/or cognitive disability, who have experiences in the out of home care system, through *Transitions from Post Care Support program* (funded by CYJMA), *ARROS Place* (DSS – Information, Linkages and Capacity Building) and young peoples' individual NDIS funding.

The cohort of young people ARROS support experience significant complexities in their lives which are exacerbated by their often hidden, intellectual and/or cognitive disability. It is important to recognise that most young people we engage with do not identify as having an intellectual disability, so often services are unaware and young peoples' voices within advocacy contexts, do not directly link to, or highlight disability

experiences, causing it to remain hidden. Due to their' experience of homelessness, and high-level of crisis, services often find it difficult to connect with these young people.

ARROS engages with young people with intellectual disability transitioning from care through a proactive, intensive, and flexible outreach model, staffed by social work and human services professionals. This ensures increased capacity of staff to respond to the significant complexity in the work, including responding to high levels of risk, systems advocacy, and therapeutic interventions, to address both the barriers young people face and to achieve the transition goals they identify.

Young peoples' perspectives: "What would it take to successfully transition from out of home care?"

ARROS prioritises the voices of young people in practice and works collaboratively with young people to seek opportunities for their voices to be heard. This document has been created through young peoples' generous sharing of their stories, made possible through their relationships with an ARROS social worker. For many young people, however, engaging in processes where they share their experiences, ideas, and concerns or hopes, for both their immediate lives and the future, is not a possibility. The barriers to connecting with formal processes or consultation (i.e., regarding post care supports) are many and diverse but can relate to experiences of trauma, intellectual disability, and the ongoing experience of living on the margins of our society due to homelessness, poverty, peer, relationship, and family violence (etc). As such, ARROS workers strive to represent young peoples' experiences as closely as possible to their truth, to ensure that while young people may not be positioned to do so, ARROS will raise their voices and ensure they are heard.

Young people need to feel safe, have a good relationship with the person they are speaking with, and to be able to take time to process information and formulate their response. ARROS workers have spent time connecting with young people to enable opportunities for them to share their ideas about what it would take to for them, and their' peers, to successfully transition from the care of child protection. Young people have stated that they would like people reading this document to know that "this is really important, if we get it right then those that come after us might have a better experience". Their hope is that their contribution assists in the development of any supports as part of either future Transitions programs (TPCS) or #MakeIt21 initiatives.

The statements that follow are directly from young people with whom ARROS engages.

Transition Planning

The moment a child enters care, you need to start planning their exit out. This is for everything, but for example, my citizenship wasn't applied for until just before I turned 18, which means I no longer have a CSO and still don't have citizenship. Every time I try and talk to someone about it, I have to talk to someone different. Having one person in Child Safety I could talk to, along with my community worker, would be really helpful with this stuff.' (Angela, 18)

We need to have more independence and say in decision making about our transition out, as my transition plan from Child Safety was to go into a homeless shelter and I didn't have any say in anything. It was all forced on me. I was homeless for a month and a half. Being present in the decisions that are being made about you while you are in care is important because once you leave care all the decisions are up to you. There's no one behind the scenes doing it for you. It's hard going from 'You're doing this' to 'you figure it out.' It helps having a worker you trust to run your decisions by and to have a worker with you when making being decisions. (Angela, 18)

Discussion

Young people clearly expressed needing more support, from an earlier age, to plan for their transition from care at the age of 18. As Angela states, many young people experience multiple CSO's across short time spans during their time in care. Having an external worker, with whom they can build a trusting relationship

with, is essential to successful and positive transition experiences. Young people ARROS supports report, and ARROS' experience through *Transition and Post Care Support* confirms, that often referrals to external agencies occur late in the transition phase, often just months before a young person turns 18. This leaves little time to build rapport with the worker to enable meaningful planning, and limited time to address barriers to accessing employment, education, and housing etc, creating significant stress. Where referrals where made, it is often short-term access to funding or support to request documents, rather than ongoing relationship-based support.

Young people further shared that they often felt like the planning phase was last minute and felt like a worker ticking boxes and accessing funds (e.g. YHARS or TILA) on their behalf, without meaningful consultation or processes that enabled their voice to be heard. Young people identified the importance of having increased opportunities to have a say in decision making about their own lives, as they moved towards adulthood, and the importance of consistent relationship with a worker to engage in this process. While young people identified the value of an external worker to connect with throughout transition (16-21) to offer this support, they also identified the need for a consistent point of contact within Child Safety, to ensure any care related questions or issues could be resolved with regards to transition (examples given were accessing their file, accessing documentation, and follow up from actions or processes that were underway while in care). It was very clear that young people would like this as an option but not an expectation that they engage.

Relationship Based Support Services

I don't want more of the same support. I want someone to be there when I need it, but I don't want them to be with child Safety. I want to be free. Michael, 21

"I don't know if making care go to 21 is a good idea if it means kids have to keep talking to Child Safety after they're 18." (Cassie, 18)

"Kids [exiting care] need a social worker who they can talk to about stuff, because after everything that happened while I was in care, I had a lot of stuff to deal with and I couldn't talk about it with my CSO." (Cassie, 18)

What helps is having a worker that is really responsive, that is good to talk to and I'm able to vibe with. I can tell they genuinely care. (Angela, 18)

"CSO's never answer their phone, they have way too many kids to deal with. I like ARROS and BEROS because I can call for support when I want it." (Cassie, 18)

Discussion

Young people identified that the transition through and from care was an incredibly difficult period. Navigating independence for the first time and the responsibility of all that comes with it (e.g. housing, budgeting, cooking and staying healthy, navigating relationships, and systems such as the law, police, health and NDIS) was incredibly overwhelming. Many young people shared that while the practical tasks that come with living independently were often confusing, what made this harder were the challenges they faced navigating this while experiencing historical and ongoing trauma (e.g. relationship violence). The need for support from a worker that listened, was respectful and they felt they could trust, was a key theme in discussions around what worked well, and what they needed more of, in their transition to adulthood.

ARROS recognises that young people with suspected or diagnosed intellectual disability, who transition from care, often have significant experiences of trauma through their experience of removal and ongoing care, as well as through their experiences of self-placing and/or homelessness, exposure to violence, and ongoing peer, family, and intimate relationships. It is also understood that the needs and hopes of these young people are

often missed due to the nature of their intellectual disability. Young people often mask their disability and can find it difficult to navigate the systems with which they are involved due to their disability. Services often don't identify young people as experiencing intellectual disability due to this masking, limiting their support.

Young people identified the importance of having worker they could 'vibe with', who expresses 'genuine care', is 'there when I need it' and is 'really responsive'. ARROS experience is that for this cohort it takes significant time investment (often between six to twelve months) to build relationships with young people so they can trust the worker to engage in meaningful support. To do this, the workers must be consistent, flexible (e.g. recognising frequent cancellations by young people as both a trust building process and/or relating to crisis and taking opportunities to connect when young people reach out), and proactive (actively reaching out to young people consistently even where there is limited contact). The work must be genuinely young person centred and be adaptive to the needs of young people with intellectual and/or cognitive disability.

ARROS experience is that these young people are most likely to fall through service cracks and require access to intensive, trauma informed, disability informed support to enable them to address barriers, and identify their goals. This is a key similarity between ARROS and BEROS practice, as reflected in Cassie's comment regarding the nature of this support, as well as the focus on capacity building that is undertaken with deep respect for young people and is flexible, proactive, and responsive. This work is undertaken by SWAHS professionals who are skilled at engaging in therapeutic work alongside engaging in practical tasks with young people.

Housing Security

What is most important is having a home to go to. I was homeless and since I've had my own place, everything has changed." Samantha, 20, (mum to a 2-year-old)

"Having my house was the biggest thing when I finished Child Safety - they should help everyone get housing at 18". (Jacinta, 20)

Getting kicked out of a SIL when you turn 18 is hard. You need support from someone, who actually cares, to find a home, learn how to budget, and cook for yourself. Kelly, 19

I feel like housing needs to be better planned for in the lead up to leaving care. Ideally having a house that is in a community, where I live alone but am not alone. I'm independent but there are people I can talk to and interact with. (Angela, 18)

Discussion

Most young people supported through ARROS have experienced, or been at risk of, homelessness throughout their journey through transition from care. The need for planning, and creative opportunities to find somewhere they could call home, also arose as a key issue of importance for young people. It was apparent that young peoples' experiences varied dependent on their housing during care, with some young people in foster or kinship care, some experiencing SIL placements and some self-placing or homeless.

For young people in foster/kinship care, there were challenges around maintaining placements beyond 18 due to the increased needs a young person might face due to their intellectual disability. Some of these challenges relate to criminalisation, navigating NDIS, and negotiating living in a family household, and maintaining positive relationships. Young people and carers talked about wanting to maintain the arrangement but needing emotional and financial resources to enable this to occur and prevent the risk of the young person transitioning to homelessness. Young people who access SIL services talked about the distress of knowing their 18th birthday meant becoming homeless, and the fear around where they would live in the lead up to their milestone

birthday. For many young people, the SIL model was not appropriate or supportive due to the crisis they experienced, thus required an alternative model to learn housing, tenancy and independent living skills. Despite these differences, the consistent theme was that all young people should have access to housing, and that while this likely looks different for each young person, housing creates safety, stability, and opportunities to begin identifying what independence means; to look forwards rather than responding to daily crisis, and to begin setting goals for the future.

ARROS experience is that for this cohort, opportunities for housing and housing security needs to be approached flexibly for each of the young people we work with. While limited housing stock and private and public housing tenancies are a major barrier to accessing housing, this cohort often struggles to maintain housing arrangements or tenancies, even when they successfully secure a home through these avenues. It is observed that common challenges to maintaining housing that are loneliness and isolation, risk of exploitation and violence by intimate partners, peers, and family (often family of origin), difficulties maintaining positive and healthy relationships, neighbour conflict and challenges with financial literacy, substance use, mental health. This list is not exhaustive but indicates some of the challenges young people require assistance with to navigate how to both access and maintain housing.

So, while increased bricks and mortar is necessary to ensure access to housing, often the issues impacting housing security revolve around healthy relationships and vulnerability to exploitation, isolation, increasing positive, natural relationships/role models in a young person's life. Examples of creative solutions might be exploring matching young people in tenancies to develop supportive households that can be tenanted in the long term, looking to potential for utilising underutilised spaces within the community (e.g., an existing resident who would like to rent a room to decrease loneliness or get assistance with mowing their law) and engaging in community development processes to build supportive neighbourly relationships and community resilience. Funding for both the housing component and community development/social work processes would be necessary to enable creative options for young people in their transition to adulthood.

Financial Assistance

Financial help would be good with more choice of how it is used. Being able to buy a car so I could work or use it to pay rent would make things easier. (Jack, 19)

Extension of care should be about payment of money to young people when they turn 18. Being in care is traumatising and having money would help young people to have a chance to start life (Max, 19)

Discussion

Young people shared that having access to financial assistance that could be used more flexibly than currently allowed would assist with their transition to adulthood. Many of these expenses would be considered rites of passage, but due to their care experience, they often feel excluded from these rites. Some young people who had successfully gained their driver's license talked about the importance of being able to buy a vehicle or use funds for its upkeep (registration and insurance costs). Having access to a vehicle enabled some young people to secure employment and gave an increased sense of meaning and wellbeing. Some young people also saw their vehicle as a safe place and would use their car to escape unsafe situations or to sleep in should they have nowhere else to stay.

Other examples of utilising funds, in a way that extends beyond current limitations on YHARS and TILA, was to use it to secure housing (e.g. to pay rent in advance), supplement their income to pay rent, and buy mobile phones. ARROS also observes the need for funding for young people to access neuropsychological and occupational therapy assessments to assist with eligibility and access to NDIS. While for many young people this occurs while in the care of child Safety, some young people fall through the cracks, particularly those self-placing, and they exit care without adequate assessment or access to disability support. While a key element across these examples is to increase the independence of young people and their opportunities for housing, employment, and to items/experiences that are important for their health and wellbeing, it is also

respectful of their emergence into adulthood and their right t0 have choice and control over decision making around their own financial choices, which is something expected of them in other areas of their transition from care. Young people saw this as key to being able to settle into adult life with reduced stress, and to be able to work towards their goals with reduced crisis.

Pregnancy and Parenting

I had a baby and they were taken by Child Safety because of my disability. This is unfair and I don't want them to experience what I did. This makes me angry and upset. I wish I had help when I was pregnant and a worker to help me learn to be a mum. Kylie, 20 (mum to two children)

When I was pregnant I was really stressed they'd take my baby because I was in care and because of my disability. But I got lots of help from lots of people that would come to my home, and it helped me to learn what I needed. Not everyone gets that though. Hayley, 19

Discussion

ARROS understands from our work with young women with intellectual and/or cognitive disability who are pregnant and/or parenting, that their roles as mothers is core to their identity. Their desire to connect with their children and to be the best mother's they can be, is their overwhelming hope for their futures. It is ARROS experience that the journey through pregnancy and parenting is often planned by young people early in their life, with the hope of creating a family of their own, and in young peoples' words 'to be the mum I never had'. This journey often occurs within the context of other complexities such as intimate partner violence, homelessness, substance use and risk of criminalisation and is often further complicated by young peoples' own trauma of removal, the grief and loss connected to their own experience of being parented, and the high risk they face of their own children's removal into the care system, which is significantly higher for parents with intellectual disability.

ARROS supports several young parents with intellectual and/or cognitive disability, however, only two young parents were in a safe enough space to be able to contribute to this document. These young women spoke of the importance of housing and having support from workers they felt safe with but chose to not focus on their experiences as parents (their quotes are captured in the housing section). For one young person whose children are in care, she expresses needing more support to connect with her children, better support to navigate pregnancy, and support from a worker who understands her, listens to her, and explains things in ways she understands. For another parent, securing housing, accessing wrap around support from health agencies and an ARROS social worker, and being actively supported to address intimate partner violence, was a positive experience that enabled her to parent her baby in the way she planned and hoped for.

ARROS recognises through practice with young people that they have limited access to information regarding reproductive rights during their transition through care. Often this occurs through school systems or Child Safety Officers or is expected to be provided by carers of young people, however there is limited consistency and access to this. Few young people report they have had conversations about sexual and reproductive health, and often state they would not engage in these conversations with adults/carers/CSOs. ARROS's observation is that early pregnancy is often planned, occurs within the context of violence and exploitation within relationships, and that there is a high rate of removal of children, for young parents with intellectual disability. Where wrap around supports have been put in place, and where the young person is centred in the work and is offered choice and control around how that support happens, outcomes can be far more positive for both the young person transitioning form care and their baby. ARROS further identifies, through collaborative practice with young people, the need for proactive education and support to enable young women with disability to develop their knowledge and understanding of their reproductive rights, and to explore their hopes and the realities of becoming a parent. This work should be both individual work in a

therapeutic context given the relationship with trauma and ongoing intimate partner violence peer led group work (which has recently been trialled with a group of young people within ARROS). In the words of young people, their recommendations are:

Recommendations

1. "Having a worker that is really responsive, that is good to talk to and I'm able to vibe with. I can tell they genuinely care."

Funding of services and support models that are able to provide **flexible proactive outreach** for young people ion the lead up to and after their transition from care to ensure continuity throughout the period of transition. Support models need to be **trauma and disability informed** and be staffed by skilled workforce able to respond appropriately to the complex needs of young people, and the systems surrounding them, in person centred and collaborative ways, to ensure young peoples' voices are always at the centre of any support/interventions offered. It is essential that service models and recognise the complexity in young peoples' lives through responsive, therapeutic practice, which includes therapeutic interventions, practical support, family work, and advocacy to support build young peoples' capacity in ways that are meaningful to them and ensures their human rights are respected and met.

2. "Since I've had my own house, everything has changed."

"You need support from someone who actually cares to find a home, learn how to budget, and cook for yourself."

It is necessary to *fund services to provide housing opportunities that are creative and uniquely tailored to young people's individual needs, hopes and goals for living independently*. A one size fits all housing model, is not identified as appropriate by young people through their feedback regarding the need for housing stability. Young people would like access to creative and diverse housing, that they can call their home, which might include support to develop co-tenancies, community models, and emergency and medium term housing.

Young people further identified the need for a worker they could trust, who could assist them to develop skills for living independently, including fostering healthy peer, household, and neighbourly relationships. For housing to be secured and maintained, services must be funded to provide assistance to develop independent living skills and knowledge, in a way that is adaptive for the needs of young people with intellectual and/or cognitive disability, across creative housing solutions.

3. "Having money would help....to have a chance to start life."
"Financial help would be good with more choice of how it is used."

Access to funds that can be used flexibly by young people to meet their diverse needs as they transition to adulthood. Young people should have increased choice and control around decision making in the lead up to transition from care to develop financial literacy skills and decision making around finances to build their capacity to do so.

4. "I wish I had help when I was pregnant and a worker to help me learn to be a mum."

Funding to develop models of support for young men and women with intellectual disability, to develop their knowledge and understanding of reproductive rights, to ensure young people are making informed choices around relationships and early parenting. Models developed must also acknowledge that early parenting is often a choice, and young people must be respected and supported in these choices, with a view to engaging in practices that ensure best outcomes for women and parents with intellectual disability.