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System Kids: Transition-Aged Youth From Foster Care to Developmental Services

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Abstract

This paper shines a light on the stories of three young adults labeled with an intellectual disability[1]*; all three have transitioned out of foster care and are now receiving developmental services in different settings in Ontario. All three have experienced varying degrees of human rights violations throughout their time in foster care as well as in developmental services. By human rights violations, we mean violations that are not necessarily always under the law, but violations to make their own decisions throughout any given day. This point shall be illuminated through the stories of the three youth who share details of these violations in concrete terms. The three have come from a diversity of backgrounds, representing what it is like to grow up in the system with Fetal Alcohol Spectrum Disorder (FASD), with Autism Spectrum Disorder (ASD), and with mobility disabilities. All three want people to know the truth about what it is like surviving the system with an intellectual disability, not only in foster care, but now, continuing to live "trapped" (as one of the young adults calls it) in the confines of the often rights-restricting world of developmental services. We balance the stories with background on the setting of developmental services and service delivery for transitional aged youth (in this paper we shall say "youth" as our co-authors have chosen) with a literature review and with interviews from developmental services staff in Ontario agency settings. This paper includes the stories of the three young adults providing their truths – painful and honest, in both written form and in graphic form. The graphic data collected provides an accessible visual depiction of the isolation and pain endured in the system.*[1]

The transition to adulthood can be an exciting but also challenging time of life for youth. Typically, youth living in a stable household have the support from their family and friends as they work towards careers, post-secondary education and living independently. The transition from adolescence to adulthood for these youth often happens over the course a number of years with the move to independence happening gradually. Youth who grew up in the foster care system, however, do not have the same experience. As Harwick, Lindstrum, and Unruh (2017) point out, "youth who age out of foster care often have an abrupt transition from being supported within a system to being completely on their own" (p. 338). The age at which youth transition out of foster care and are required

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[1] Please note that we use the term "labeled with an intellectual disability" in order to preserve a "people first" approach to language. In other words, the person comes before the disability, and is much more than their disability.

to be completely independent from support also is substantially different from youth not in care. For example, studies show that in Canada 93% of 18-year-olds and 41% of those aged 20–29 live with their parents (Gough & Fuchs, 2006). Youth in foster care have a completely different experience as care ceases at a much younger age. Youth in Ontario no longer qualify for protective intervention services past the age of 16 (Gough & Fuchs, 2006, p. 2). Once youth reach the "age of majority" (18 years) they are said to have "aged out" of foster care and are on their own emotionally and financially without many of the supports that the general population take for granted (Gough & Fuchs, 2006, p. 2). Youth in foster care in Ontario report "feeling a deep sense of abandonment when they formally age out of the system and anxiety about the impending lack of support after leaving care" (Kovarikova, 2017, p. 6).

Adding disability to the mix only results in compounding the barriers that these foster youth face, including critical issues such as obtaining housing and medical care, and overall emotional well-being.

There have been many studies on youth transitioning out of the foster care system into adulthood. Conversely, little research has been conducted focusing specifically on the experiences and outcomes of youth who have disabilities as they age of the foster care system (Hill & Lightfoot, 2008).The research for youth with disabilities transitioning out of foster care tends to focus on youth with Fetal Alcohol Spectrum Disorder (FASD). However, when it comes to youth labelled with a developmental disability, there has been limited to no research. Hill and Stenhjem (2006) point this out in their research highlighting how Chapin Hall's 2005 longitudinal Midwest Study of youth aging out of foster care neglects to include youth with developmental disabilities, although half of the youth in this study reported receiving special education services. They further highlight how "disabilities are rarely studied in relation to child welfare and are even less frequently considered in the transition from care" (Geenen & Powers, 2006, as cited by Hill & Stenhjem, 2006, p. 2).

This is particularly problematic since 82% of youth in care in Ontario are diagnosed with special needs (Benson et al., 2012, as cited by Kovarikova, 2017). For example, studies of children in care in Manitoba found that "17% of children in care in Manitoba in 2004 had been diagnosed or suspected of having FASD" (Gough & Fuchs, 2006, p. 1). Also, according to the United States Centers for Disease Control and Prevention (2014), Autism Spectrum Disorder (ASD) affects 1 out of 68 children in the US (Havlicek, Bilaver & Beldon, 2016, p. 120) and studies show that the prevalence rates of children and youth with ASD in foster care is "significantly higher than in the general population" (Bilaver & Havlicek, 2013 and Hill, 2012, as cited by Havlicek, Bilaver & Beldon, 2016, p. 120). For these reasons it is important that specific measures are provided to protect these vulnerable groups.

Legislation governing rights for persons with disabilities includes Ontario laws related to accommodations. Specifically, the Ontario Human Rights Code (1990) sets out specific and enforceable legislation for persons with disabilities to receive accommodations related to disability when receiving services. The Accessibility for Ontarians with Disabilities Act (Meilleur, M. & Ontario, 2005) is legislation outlining the requirement that agencies must take certain steps in delivering services to persons with disabilities. The Substitute Decisions Act (1992) and the Health Care Consent Act (1996) both outline legal criteria for determining when a person can make decisions that are fundamental to their well-being. There are law reform efforts underway in Ontario for strong revisions to the current legislation with a push to move toward the Supported Decision-making laws that are in place across Canada in British Columbia, Yukon, Alberta, Saskatchewan, and Manitoba. The concept of Supported Decision-making is one that has received recognition and has been adopted by places around the world such as Sweden, Australia, and Ireland. (Bigby, Whiteside, & Douglas, 2017). It promotes a system of decision-making that provides increased autonomy for persons who need support in making decisions. The Convention on the Rights of Persons with Disabilities (CRPD) is an international law that sets out the rights of people with disabilities (United Nations General Assembly, 2007).

Within the CRPD, Article 12 states that people with disabilities have the right to legal capacity on an equal basis as people without disabilities (United Nations General Assembly, 2007). Legal capacity refers to one's autonomy to make their own decisions without findings of incapacity by a capacity assessor. A capacity assessment is a formal assessment about a person's ability to make their own decisions about property and personal care. Article 12 also states that governments must provide access to supports to help people to exercise their legal capacity. Additionally, Article 12 states that governments must put safeguards in place to prevent abuse of people with disabilities who try to exercise their legal capacity. Let us keep the CRPD in mind when we read the stories of our three youth in the body of the paper

Background

As noted above, it has been well documented that youth leaving foster care experience many challenges that affect their future adjustment and functioning as adults. For example, Courtney (2001, as cited in Osgood, Foster, Flanagan, & Ruth, 2014, p. 43) found that "43% of the males in their sample and 32% of the females had experienced one or more of the following within twelve to eighteen months of leaving foster care: homelessness, incarceration, serious physical victimization, sexual assault, and rape." The Our Voice, Our Turn report published by the Provincial Advocate for Children and Youth (as cited in Kovarikova, 2017) also highlights that youth outcomes after aging out of care include "low academic achievement; unemployment or underemployment," as well as "early parenthood; poor physical and mental health; and loneliness" (Kovarikova, 2017, p. 4).

Research also tells us that foster youth with developmental disabilities aging out of care, including those with ASD, have "heightened risks and vulnerability" (Osgood, Foster & Courtney, 2010, as cited in Havlicek, Bilaver & Beldon, 2016, p. 119) and experience a wide range of difficulties similar to their non-disabled peers such as: drug and alcohol abuse, high rates of teenage pregnancy, homelessness, criminal justice involvement, living in poverty, and chronic medical problems (Hill & Stenhjem, 2006). It is also important to note, as Osgood et al. (2014) point out, that "problems in any one of these domains can make success in another less likely" (p. 33).

In this paper, we want to improve our understanding of how developmental services can better support youth who have come from foster care, by shining a spotlight on the stories directly from the youth, as well as by looking at what research says. Our paper's main focus is hearing their stories, which are told in their own words, and supported by images that were developed using processes of collaborative graphic research.

Methodology

At the heart of this paper are the narratives and graphics of youth labeled with an intellectual/developmental disability. The stories provided by the youth co-authors were transcribed by Maja Rehou and Sue Hutton. Stories were transcribed with editing in order to remove pauses and hesitations. The youth co-authors reviewed all transcriptions for accuracy and approval. Headings in the subsections of the stories are based on content directly from the youth. We contextualize these stories and images by intertwining them with background information. This background information consists of a literature review and one-on-one interviews with staff serving these youth. We interviewed seven staff members from across Ontario over the course of five months. The interviews consisted of open-ended questions. Themes and recommendations that emerged from these interviews are woven through the body of this paper. Our goal is to add to the knowledge regarding transition aged youth receiving developmental services in Ontario.

Based on past success using arts-based methods in conjunction with personal narratives of institutional experiences (Hutton, Park, Levine, Johnson & Bramesfield, 2017), this article employs a similar approach. The narratives of young people who have recently transitioned from foster care and who also access developmental services are juxtaposed with collaboratively generated images that communicate their feelings about and experiences of foster care.

Using art-based research and collaborative knowledge production techniques is becoming more common, particularly in the social sciences (Leavy, 2015). More and more, creative visual methods are considered to be accessible, expressive, and reflective practices that engage participants themselves in knowledge production, a process known as enabling methodologies (Gauntlett & Holzwarth, 2006). Enabling methods counter power imbalances in research, and particularly power dynamics that exist between adult researchers and youth participants, by engaging participants directly in the processes of knowledge production, (Barrère, 2003; O'Kane, 2008). Enabling methods invite young people into the research in a different way, moving the focus away from research ON or ABOUT youth to research WITH youth (Christensen & James, 2008). Arts-based methods also offer an approach to meaning-making that communicates emotionally-charged material by circumventing words or attempting to answer questions that lack straightforward answers (Springgay, Irwin & Kind, 2005).

The images featured in this article were generated during sessions (both one-on-one and group) with the youth, using collaborative, arts-based graphic elicitation techniques. The transition-aged youth were engaged in graphic research processes to assist in making their experiences in foster care visible and understandable. The youth were provided with an option of drawing their own image, or having one of the co-researchers assist with drawing it using a collaborative co-creation process. In this process, the youth provided the direction as to what image from their story they wanted to have in the paper. They directed the co-researcher to sketch it out and changes would be made as the youth chose. One of the youth is an artist, and chose to have the co-researcher draw part of the drawing, and she then took over and completed it. Time was taken to ensure that the image depicted the scene they chose to convey from their foster care experience.

Although the youth are co-authors on this paper, due to the trauma of their stories in foster care, plain language written consent was obtained and the option to withdraw from the process at any time was underlined and reinforced regularly.

The youth had relationships with the co-authors through previous advocacy work in developmental services and a trust was previously established. Ongoing phone calls and communication took place to ensure support was there for the youth during the telling of these stories. Every effort was made to ensure the process of creating the paper was as accessible as possible.

Our Stories Entwined With Background Literature and Interviews With Staff

Seven developmental services staff were interviewed to explore their perspectives on providing services to transition aged youth in Ontario. All staff interviewees agreed that youth labeled with a developmental disability aging out of foster care were not given enough opportunities to acquire the skills needed for independence. They also agreed that these youth face long developmental services waitlists to get access to adult services and programs that support their transition into adulthood, including access to extremely limited affordable housing. All these waitlists and lack of available supportive programming and lack of access to housing can lead to these youth going into crisis as they face the experience of very little support in life.

Staff interviewed agreed that transition aged youth are provided limited experiences doing things for themselves in foster care. These things include basic daily living skills such as cooking, shopping for food and clothing, and banking. Staff reported that youth were so well protected while in care that they did not have the opportunity to take risks and learn from their mistakes while they still had support. As one developmental services agency staff interviewee stated, "youth need opportunities to build capacity and resiliency while still in care." From an agency/sector perspective staff felt it was complicated supporting and providing service for transition aged youth because, as Crown Wards, they are over protected and frustrated by being told what to do for so long. Staff interviewed reported that when youth transition out they often want to take risks and "do and try everything" because they had no freedom or opportunity to make choices while in care.

Staff felt that youth not having enough opportunity to make choices in their services is an issue of infringing on their right to make choices. Youth are not provided with opportunities to really choose who to live with and spend time with because of system constraints and waitlists, funding, services and appropriate housing.

Staff interviewed also felt these youth are like typical teenagers who like to push boundaries, but they never had a chance to do so in foster care. Youth want to do things that other youth are doing, such as have friends, hang out with them, and make choices to fit in. At times, these choices are related to risky activities such as drugs and stealing. Staff reported that there is a risk of them then becoming involved in the criminal justice system as a result. It was also a staff perspective that these youth crave more social acceptance because they were socially isolated as a result of being in foster care or in school special education programs. As a result, they are very vulnerable to being taken advantage of.

We will see some of the perspectives of staff echoed in Sarah's story below.

Take a Walk in My Shoes

Sarah's story: We Are All System Kids
By Sarah Lyttle

Figure 1. Image co-created by Sarah Lyttle and Graphic researcher Noah Kenneally. The image shows a drawing of Sarah walking down a path in the dark, stepping out of one shoe, leaving it for the viewer to step into.

Change is a process, not an event. It doesn't happen all at once. 18 and all of a sudden I'm out in the world. The system never helped me prepare for the transition. I grew up as a system kid, and I'll always be a system kid. We all are.

A number, not a person. *I'm not Sarah Lyttle in the foster care system. I'm child profile 14541. That's how I'm known in the system. I'm a number. I'm not an actual person. I'm a number that's it. It's very discouraging… like it's not just fair.*

I have three huge binders that are my case files from the Toronto Children's Aid Society. These files start from 1992. I was born in 1991. So literally a year after I was born this case was opened and there are a lot of not so nice things in there that are written about me or things they had done are not right, not ok whatsoever. I read a lot of this and they withheld it from me when it actually first came in. They withheld it from me for almost about a year. They didn't want me to see it at all because they were afraid what it was going to do to me. But really honestly just with the things I've read, I couldn't understand why they held it from me just because of things they said about me or my family or just experiences and stuff.

I know the system, I don't know family. *Yes, I was moved 18 different times …and it's not just foster homes it's also group homes as well too. It's extremely discouraging. Mmm because you will move into a home sometimes and some of the foster parents… I think they mean well but they will sit there and be like "ohh we're going to be a family, it's going to be fantastic, you're going to be here for a long period of time" and then all of a sudden I have a worker showing up at my school taking me to a new home. Umm it's not the funnest thing at all whatsoever. I eventually learned to cut off everyone that I was living with in the home. I didn't want to talk to them, you're not my friends. I have nothing to say to you, I really don't. Umm it's really unfortunate because some people I should have really given the chance to but I just couldn't do it because 18 different placements… it's really not fun. Knowing what it's like to have a family? No. I know the system. I don't know family. I don't know anything at all about family at all whatsoever. It's really not a fun experience…discouraging…yep.*

We shall pause from Sarah's narrative to discuss the research.

Instability in care: What the Research Says

Just as Sarah talks about being plucked by the system from a "home," and instantaneously placed in another in a different part of Ontario, the research confirms her story. Lack of continuity caused by multiple placements in care is a key factor highlighted in the literature when it comes to why transitioning to adulthood is so problematic for youth with disabilities in care. For example, Gough and Fuchs (2006), in their report, state, "youths in care with FASD experienced from one to 20 residential placements during their time in care" (p. 3) and a study conducted by Harwick, Lindstrum and Unruh (2017) found that the youth they interviewed

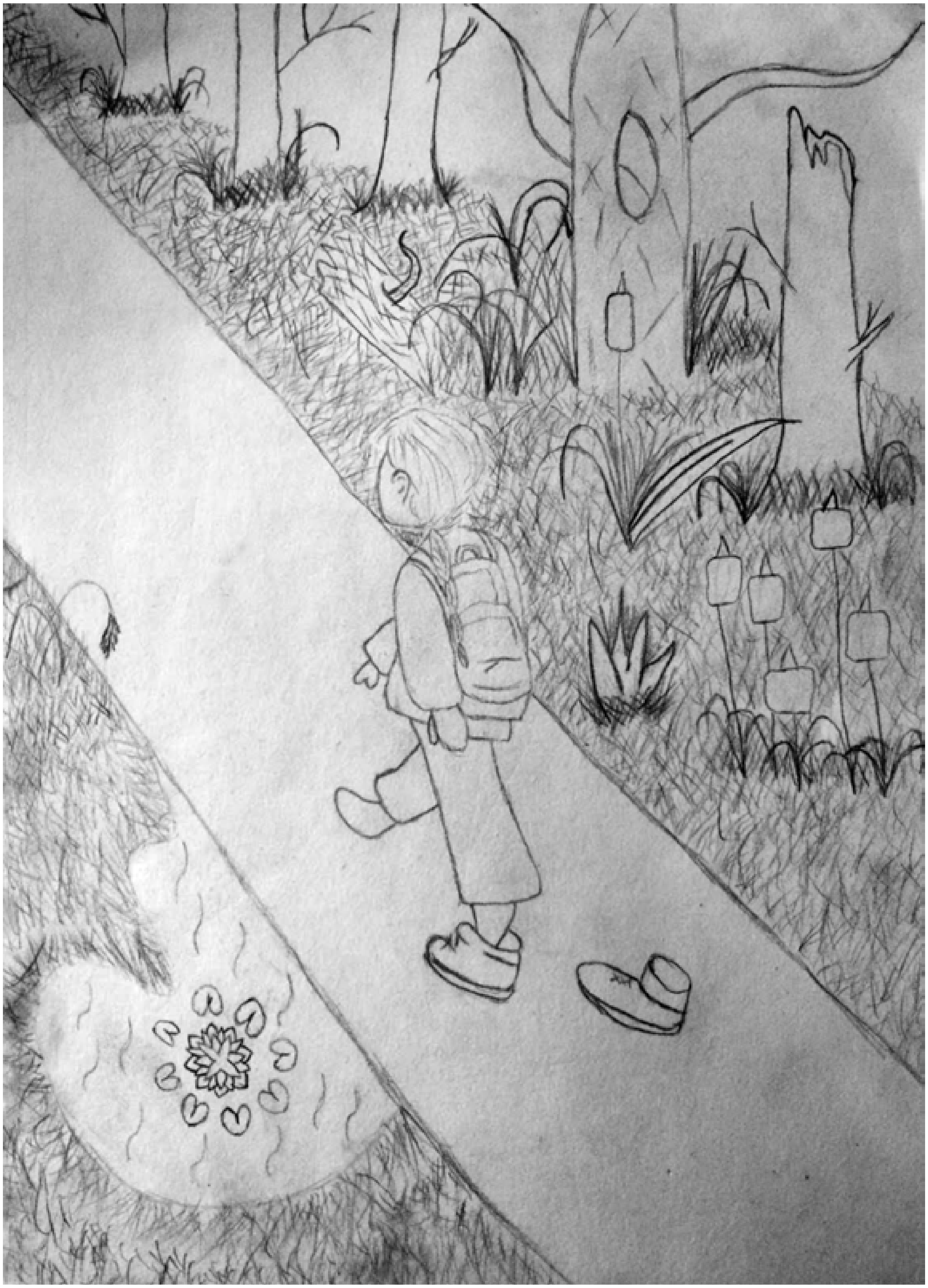

Figure 1. Image co-created by Sarah Lyttle and Graphic researcher Noah Kenneally. The image shows a drawing of Sarah walking down a path in the dark, stepping out of one shoe, leaving it for the viewer to step into.

experienced between four to 15 placements while in care. Kirk and Day (as cited in Kovarikova, 2017, p. 11) reported that foster youth may move up to three times per year on average." This "placement impermanency" is what appears to "affect the development of meaningful relationships" (Kovarikova, 2017, p. 33).

Instability not only occurred in living arrangements, it also occurred with staff supporting youth. For example, research by Gough and Fuchs (2006) found that youth had a number of child welfare workers while they were in care ranging from two to 15 workers per youth, with an average of 5.7. This lack of stability in care workers and other social connections due to being in foster care also leads to a lack of supportive relationships, especially at a critical time when youth need adult mentors to help guide them through major life decisions such as career planning and post-secondary education. Not having an adult mentor also makes it difficult for youth with disabilities to navigate through adult disability services and funding sources. Developmental services are also notorious for high staff turnover. When these youth enter into developmental services, they often find themselves having the same experience of instability in staffing as they did when in foster care. Developmental services workers are among the lowest paid in Ontario, and after pressure from unions, steps are being taken by the Ministry of Community and Social Services to increase wages to help with staff retention (OPSEU, 2014).

Since schools often facilitate transition planning efforts, Gough and Fuchs (2006) highlight how transition planning is also interrupted by placement instability because of the subsequent transitions to different schools. Research by Kovarikova (2017) revealed that "every time a youth move[s], they lose four to six months of academic progress and then struggle to make up the loss over time" (p. 9) "due to the disruption and logistical coordination between academic and child protection institutions" (p. 11).

This instability also has a negative impact on the mental health of these youth who are not only dealing with the trauma caused by going through many transitions while in care. Compounding that is the fact that the "sexual and physical victimization" they often experience while in care "puts them at a particular disadvantage" (Osgood et al, 2014, p. 35) with regards to mental health. Research is consistent in finding that former foster youth experience mental health problems during the transition to adulthood (Osgood et al, 2014, p. 36). Studies show youth with developmental disabilities also have a high rate of co-occurring disabilities. For example, 88% of youth with FASD have co-occurring disabilities, which includes 46% of youth diagnosed with FASD also having a mental health disability (Gough & Fuchs, 2006, p. 1).

Consistent with the lack of rights that foster children have to make their own decisions, Sarah's story describes how she sees her rights being violated in multiple ways. Being denied the basic right to be involved in decision-making is something all three stories share – from their time in foster care to their time in adult services.

We will now resume Sarah's narrative.

Where are decision-making rights?: Office of the Public Guardian and Trustee. *I was not very involved at all in my plan of care in foster care. The Provincial Advocate for Children and Youth office says if you are 12 or over, you have the right to help make your plan of care. They never involved me in my plan of care in the system.*

Then when I was transitioning out of care, I got assigned a Public Guardian and Trustee with Toronto and it has been not the greatest experience at all whatsoever. They were supposed to transition more funding for me when I moved independently and my money has been decreasing since I've been here. Like you can't get a hold of them half the time, like at all whatsoever, which is not very fun because if I want to go and do something personally and I needed some funding I can't get a hold of them so I have to cancel my plans half the time.

Where are health care rights?: Depo Provera. *I was put on Depo Provera against my will. They just put me on it. That was the worst needle in the world. That's all I can say about that. I started taking this when I was 14 years old. They told me it would be good for me to take. Obviously because I started it as a teen. But I did not realize nor was I told the side effects of Depo Provera could actually do. I stopped taking Depo Provera when I moved here into the* *city. I did not know that I had a choice not to take it. I thought I had to take it because that is what I was told up until I moved here.*

Finally transitioning to developmental services. *I had to meet with multiple agencies to see what the options were. It was a lot of pressure. First thing was the DSO [Developmental Services Ontario] then I got contact with an agency. Literally I met them and they were like we can do all this work and in 9 months we will meet again. Awesome cool. Then 9 months again same story. I literally said no thank you and I left. I have nothing to say to you either. After that I met a program. I didn't like them whatsoever. It was when I met with another agency, and they actually had a solid plan. This is what it looks like. This is what a budget looks like. This is how we help and support you. We will show you a couple of places. We have a couple places available. They actually came with a plan. I didn't have to say much to them. He asked how they could help me be supported in the community and how they can help me with day to day living. I was taken aback because that was the first time anyone asked me that type of question.*

My 21st birthday consisted of me moving into my first place. I didn't really have a choice. I had to go at 21. I went to a bachelor apartment. That was probably one of the worst experiences that I had. It felt like four walls closing in. There was not a lot of support. I struggled a lot with you know just dealing with day to day things. Just because of the fact that I was not fully, properly supported to do the transitioning part of it. So it was very hard for me. It became very stressful with no supports in the bachelor. Because of my anxiety I went back to foster care. I had nowhere else to go.

I had to move back into the foster care system and stay in a foster house for another two years, which while trying to get into a program, I actually struggled with addiction for those two years. I kind of became a little bit of an alcoholic and even when I came down here I was still drinking…drinking a lot of alcohol. Some people were really shocked at the amount I would drink. They were like my liver…your poor liver but I'm on the healing track now. Actually my last drink was in January. I haven't drank since then. It's hard when it comes to addiction.

I have FASD. I'm quite well aware about how my disability affects me on a day to day basis. I know sometimes my communication… it's motor skills and memory loss too. When I'm over stimulated I get very forgetful.

Sarah Has a Support Worker Whom She Refers to as Her "External Brain" Sometimes

It's important to have a staff who is consistent with me. My staff now is. She's like tomorrow. Can we do it tomorrow? Yes let's do it. That's what I need. Not someone who will call back in 9 months. My cat Donatello has been with me through all my changes. He's consistent.

Sarah clearly states the need for consistency in people around her. The research echoes her sentiment.

Lack of supportive relationships or connections with caring adults. In the literature reviewed, youth indicated the need to have at least one supportive adult relationship as they make the transition to adulthood (Office of the Provincial Advocate for Children and Youth, 2014). Instability and lack of continuity in care, as well as the social isolation that youth experience due to having a disability (e.g., being placed in special education classes) leads youth to have an inability to form core relationships.

Gough and Fuchs (2006) suggest the importance of ensuring youth in care have attachment to at least one significant adult who is able to act as a mentor (p. 2). Hill and Stenhjem state: "the consistent presence of a single caring adult has been shown to have a significant positive impact on a young person's growth and development" (2006, p. 3). However, as Havlick, Bilaver and Beldon (2016) point out, relationship building needs to be persistent, with consistent communication and information sharing, if it is to be successful (p. 119).

Also, the staff we interviewed noted that the lack of healthy attachment patterns formed, due to the abuse and neglect the youth experienced with biological family before going into care, is also a factor that can diminish Transition-Age Youth's (TAY) capacity for acquiring supportive relationships.

Staff interviewed pointed out how a large percentage of these youth live in congregate care. Since congregate care facilities are generally staffed by relatively young shift workers who tend not to stay in their jobs very long, youth in congregate care may find it difficult to form the kind of lasting relationships with responsible adults that will help them move towards independence. They also suggested another way to ensure these youth form social attachments is through fewer placements and more stability while in care. Staff reported transitioning to adulthood can be a huge re-socialization process.

As Sarah's story continues below we see the impact instability and poor-attachment patterns have had on her life:

I was in foster care, I had been going to the same access centre to see my biological mom and dad for years. It's kind of like a school. Literally like an elementary school. I went there for years actually. When I graduated from Grade 8, the two people standing beside me in my photo I had been living with them for five years. They are literally my forever mom and dad. They are my mom and dad. No one else is going to be my mom and dad. My own parents are not my mom and dad. They are very supportive people. I moved in with them when I was 10 and still even to this day I still have contact with them. I'm still talking to them. Going out for dinners every now and again. They're a huge part of my life, like massively. Then I graduated from Grade 12. I'm actually the first in my family who has graduated from Grade 12.

Some people were with me there through thick and thin. I struggled with drugs as a teen. There was an amazing lady who was the director of a foster care home. She once knocked down a drug house with 12 cops because that's where I had been hiding out. And this lady. I really put this lady through hell for three years. I had 43 missing persons reports while living in her house because I struggled. I didn't want to be at her house. I didn't like her at the time but you know I feel bad right now to this day that I put that lady through that. But she stuck with me for three years. She put up with that.

And my dad. I'm going to have to say that I don't have a love/hate relationship towards him but what I will have to give him out of everything that's ever happened is that he's always been there. Dead as a dog he'll show up to my visits. At my graduations he's there. Anything really important he's there. Grade 12 grad. When my dad heard about some of the things that were happening to me he was like whoa… He wanted to do something but he had no rights because I was a Crown Ward. He did not have the legal right to do anything. I was basically government. Sometimes you're born into a family that can't help themselves. It's very unfortunate even with a large family. I don't even know half of them. They had nothing to do with my father just because of what happened to me and my family.

I don't really talk about my mom too much because she was not a very huge support in my life. She stopped seeing me at the age of 10 and then when I was 16 I had got a phone call basically that she had passed away. I had no feelings towards that. Later on in my case files, I found the reason that she had stopped seeing me was kinda not nice. She got upset because I was calling my foster parents mom and dad. So she felt I was replacing her and stopped seeing me just because of that, which unfortunately happens sometimes.

Art helped through the changes. *Art helped me through changes. While struggling in my teen years, I found art was one of my massive escapes. So I would draw a lot just to escape reality and when a lot was going on around me.*

And now I'm heavy into gaming. I love gaming. I play this one game called Minecraft and I have been creating a Lord of the Rings. I'm absolutely obsessed with Lord of the Rings. I love Lord of the Rings.

What do I feel like I need from staff? *Stability is so important. It's really hard when you have workers, foster parents, staff, one-to-one workers from different agencies. When you have so many people talking about the same thing, you're totally hearing different messages from everybody. That's really hard. I have seen people become numb with the information. Even me, myself who has been told all these different things from all these different people, it's like in one ear and out the other. I didn't want to listen to it. It was too over stimulating sometimes. Even with the transitioning, you become numb. It's like when I was at school and they told me to pack my bags. When I asked why they said I'm going to another school. I said "oh ok." To me it was just another day.*

They should consider changing how they do things because I may have had friends at that point. I've lost a ridiculous amount of friends because of transitioning and that's not cool because it basically impacts my communication with other people in the world. I have only one friend that I kept in contact with from elementary school. But the amount of times that I moved I could talk to her but I couldn't maintain a friendship. So you're always constantly *making new friends and meeting new people and stuff. It kinda sucks. It really does.*

You eventually…some people… I don't really want any friends. I'm at that point now that I'm living here in the city. I don't want to make any friends because I still live in that brain mentality, I'm going to move. I'm going to be going somewhere else. So it's a struggle, it really is.

Despite all that she has gone through, Sarah's story is one of deep strength and resilience.

I have a poster on my wall. Pretty much defines me. I get to look at every day. This definitely defines who I am. 'Don't let anyone hold you back. Take risks. Spread love. This life is your message to the world. Let it be extraordinary'. [End of Sarah's Story]

It Was a Sad Story: By Kevin John-Head

The beginning of foster care. *I moved out from my mom's apartment to a group home. It was a different type of home. It was a house. It was in Scarborough.*

It was different living there. It was hard living with different types of people because I was there and my friend was there. My friend grabbed my arm and pinched me very hard. It's very serious.

There were two group homes I went to… for six years and then I moved to foster care. I'm not sure how old I was. There was a staff office there. I would go swimming for exercise when I was a kid. Staff were good to me.

I went to a special school. It's a special place where special people go there.

Figure 2. It was a Sad Story. Image co-created by Kevin-John Head with graphic researcher Noah Kenneally. This image shows Kevin lying in his bed in his room. The bedroom door is locked with two locks and bars across the door from the outside.

I was scared at the group home. *When I left that foster care I went to the group home. I was scared because I had never been there before. Kids had a problem in this group home. You would get serious consequence. People would tell me to go upstairs and say "good night Kevin." It was very serious. The staff had an alarm on the door of my bedroom. The alarm would go off when I went to the washroom. Staff gave me time out in the kitchen. I came home from school and I would get consequence. Staff told me I can't go out and I can't watch TV. I don't know what the consequence was for. I had to stay in my room for seven hours at bedtime. When I came home from school staff would give me my meds and I would have supper. After supper I would have to do some chores in the house. I would wash dishes. I would do some mop in the kitchen, living room and dining room.*

Staff weren't nice there. *They would yell at me – "Kevin can you go upstairs to your room or you would get grounded for two weeks." No TV, can't go outside and do things, do nothing, just stay in your room, that's it. I could play with the toys in my room. I had a roommate and he would be in the room too because he was grounded.*

After the group home (for four years) I went to another group home for four years. I was still a teenager. The second one was a better group home than the first group home. It had hard wood floors. There was a brand new kitchen, brand new basement, brand new couch it was beautiful there. Staff treated me very well at that group home. After that group home I went to another group home. I was in this other group home for three years before I moved to where I live now. At the third group home the food was locked up. The fridge had a lock too. Staff would say "Kevin come here – sit down or you will go upstairs. Kevin do you understand me? You're going to go upstairs or you will have a serious consequence."

I was scared. All the kids were scared. I did not know what was going to happen to me. Staff should protect me, protect Kevin. It's very important to me, so important.

It's not just me. It's everybody. It should not happen to anyone. *That breaks your heart right? It will not happen ever again. It's like a terrible roller coaster ride. Up and down.*

The transition from foster care. *Group home staff told me I was moving to a new place a year before I moved. I was 22 when I moved to where I live now. At the group home they taught me how to cook like chicken, rice and vegetable – my favourite food.*

What do youth leaving care need? *I needed support. I needed to learn. I wanted to learn basketball and track and field. I used to do Special Olympics when I was in the group home. Teach staff how we talk– to understand us. Staff never understood me. I should have been taught more in school like how to read and write.*

What it's like today. *I like where I am now in independent living, because they support me with things like my budget. I go out now and have fun. I go to rights groups, self-advocates groups and People First. I'm a treasurer. I won elections. I'm so excited. I'm part of relationship working group. I have a busy life. I have a whole life to go. I want to be a better person. I want to be open.*

Congratulations to me, Kevin John-Head. I'm going to be a successful person. [End of Kevin's Story]

Transition aged youth need trauma/mental health support. Through Kevin's story we see the physical and emotional trauma that he experienced while in care. Staff interviewed expressed how youth who have gone through this type of trauma need emotional/psychological support. However, there are waitlists for this type of support, or youth refuse this service. Their trauma history needs to be addressed regardless of what we feel their capacity is. One staff interviewee stated how we also need to provide trauma support to caregivers/foster parents if the child is a victim of trauma because of the impact of vicarious trauma from the child they are supporting. According to studies reviewed by Osgood et al. (2014), "former foster youth suffer from more mental health problems than the general population" (p. 34). These mental health problems can negatively affect other outcome domains and are less likely to be treated once they leave care (Osgood et al. 2014, p. 43).

Mental health issues can be exacerbated if these youth also do not have skills and abilities because of disability or special education. Therefore, as Hill and Stenhjem (2006) suggest, youth would benefit from individual/group counselling and service coordination (p. 1). As Hill and Stenhjem (2006) also suggest, having a required transitional independent living plan supports youth to develop critical competencies; obtain education, career counselling, physical/mental health care, housing, develop relationships with caring adults, access community resources, public benefits/services and acquire daily living skills (Pokempner & Rosado, 2003, as cited by Hill & Stenhjem, 2006, p. 1) because "'aging out' without a permanent family and/or adequate preparation for adulthood is a crisis. It is a personal injury to each and every youth in care and a public emergency for our national child welfare system" (Frey, Greenblatt, & Brown, 2005 as cited in Hill & Steinjem, 2006).

The Need for Multi-Sector Collaboration Between Ministries

A strong recurring theme repeated throughout the interviews was the need for a systemic-collaborative relationship between agencies before and throughout the transition process so staff have access to the appropriate expertise when it comes to supporting these youth. One staff interviewed highlighted this when he said, "there needs to be a better communication system between sectors."

Currently, as staff interviewed mentioned, all systems work independently. Collaboration needs to be at the Ministerial level (i.e., Ministry of Community and Social Services and Ministry of Corrections) but at the sector and agency level as well. For example, one staff interviewee suggested that Children's Services work closely with developmental service sector agencies while the youth are still in care so that staff can get advice from developmental service staff as to where to get the best supports for these individuals when they start to transition out of care. One staff interviewed said if support is not put in place before these youth transition out of care they will, "fall through the cracks."

The importance of interagency/sector collaboration was also mentioned in the literature. As Frey, Greenblatt and Brown (2005, as cited by Hill & Stenhjem, 2006) point out "coordination of transition planning among key agencies and systems is imperative" (p. 3). Stroul and Friedman (1986) agree that "interagency collaborations" are needed because they "bring together and engage critical stakeholders in a coordinated and integrated effort" (as cited by Havlick, Bilaver & Beldon, 2016, p. 119). Research also shows this lack of collaboration results in no "single point of access for information about services (Havlicek, Bilaver & Beldon, 2016, p. 126)." Poor coordination between child welfare and adult service systems or "silos" makes transition to adult services/systems "confusing" for both service providers, as well as foster youth (Havlicek, Bilaver & Beldon, 2016, p. 126). ***Earlier and longer transition planning.*** Staff interviewed not only agreed that there needs to be more collaboration between sectors, but they also felt there needs to be more time (i.e., one year) in the planning process, so there is time to put the supports in place before the person is actually transitioning out of foster care. Currently, according to staff interviewed, transitional planning/support from child to youth is only approximately one month. Child and youth sectors need to come together in the transitional planning process. The system needs to prepare youth/foster parents about the shift in the system (i.e., getting into DS services, ODSP) that will happen after they turn 18, and it should be started when they are 16 years old. The need for better cross sector collaboration and earlier on will lead to better transition planning. The consequence of having poor transition planning is exemplified in the anonymous youth's story below:

Trapped: By Anonymous

I would like to have no name associated with my story. I don't feel safe where I am living now, and don't want them to find out I am saying this. The drawing I created – Trapped – that's what it feels like. It felt like that when I was in foster care, and it still feels like that today. I feel like I'm trapped – in jail.

To start with, it's [developmental services] not a pretty picture for people coming from foster care. It's sad now. Because I don't to this day know what developmental services is. I don't even know why I was put here to begin with. I don't even know what my problem is. What does this mean for my future – whether I even have a future, or whether I need to go find a future somewhere else. I'm still young. I don't even know if I belong here. It's sad. Nobody tells you anything.

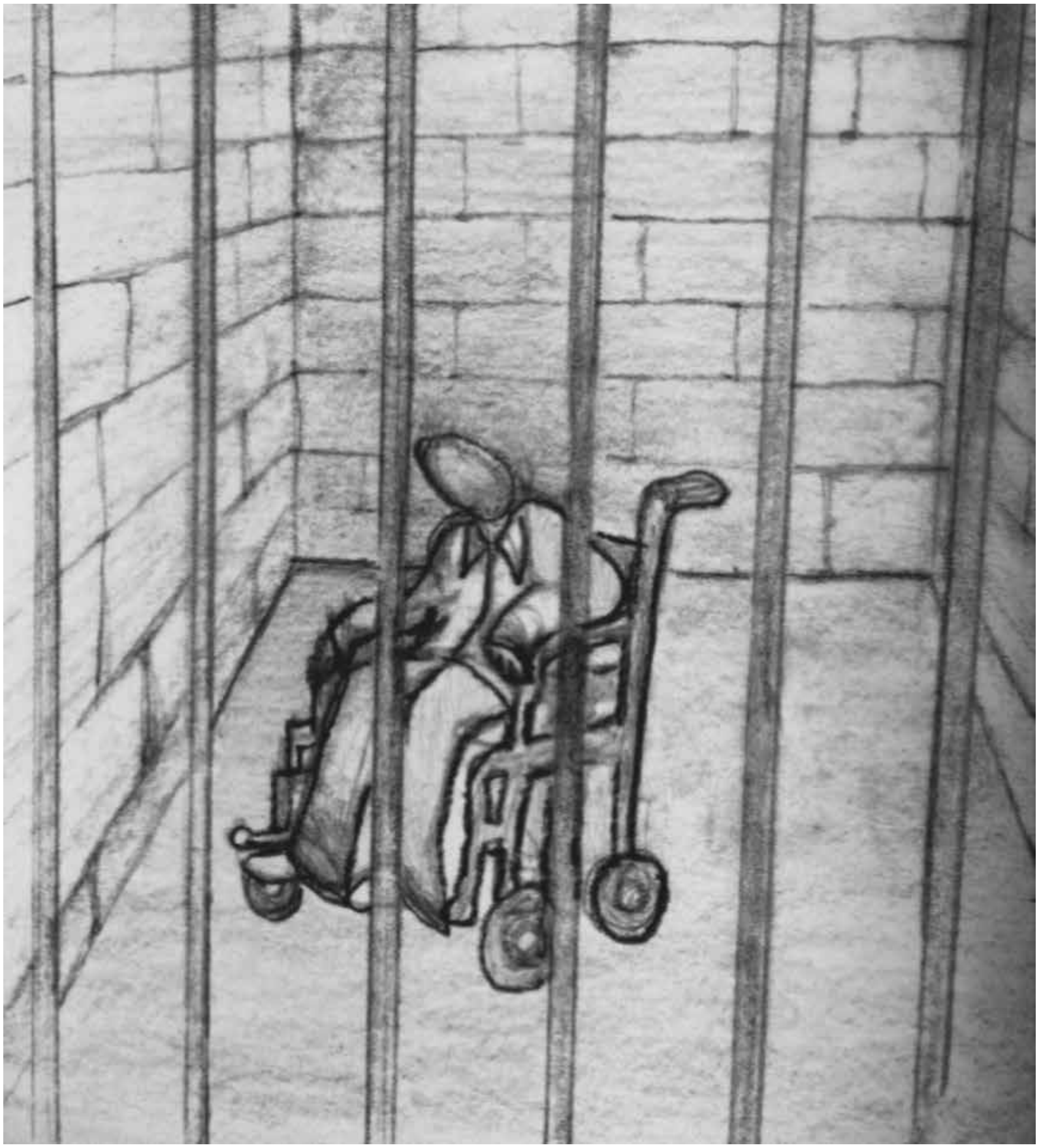

Figure 3. Trapped. Image co-created by anonymous and researcher Sue Hutton. This image shows a figure slouched in poorly fitted pyjamas in a manual wheelchair with no foot rests. They are seated within a jail cell, with no windows.

I also want to say to whoever is still in the foster care system today; you need as many people as you can on your side to fight for you. I only had CAS [Children's Aid Society] and my foster family. My foster family didn't have much say, because my biological family still had legal rights. I wasn't a crown ward. I was placed under something called a special needs agreement.

Little me in foster care. *Just imagine – little me being carried down 12 flights of stairs to visit my family member. It was bad. Children's Aid didn't protect me. On the visits they were drinking and on all kinds of medication. They even hit me with a converter. Apparently they hit me because I was crying – because I didn't know what was going on. And they were sleepover visits. My family member was addicted to heroin. CAS didn't keep me safe from* *harm's way. This is why I want NO contact now. They're not family to me. They are just biologically related to me.*

This is why the kids have behaviours. They get punished for something they didn't do. I would get grounded when I was communicating my frustration. I would hit and bite and get angry. Of course I did. I was just communicating.

At 18, I was still being made to go visit my family member with the addictions. I was supposedly transitioning into this adult world. The social workers thought it was best for me to grieve – to figure out who I am as a person. To be honest, I wish I was adopted. No one should ever have to live through that turmoil.

Children's Aid did nothing to protect me. *Then I was being abused in the second foster home. I never got a wheelchair accessible shower in foster care. My second foster home I moved into when I was 13 had stairs. Imagine being told in six months you'll have everything accessible. Nope! I had to get sponge baths. I was allowed to have a shower once a week at the goddamned swimming pool. I was only allowed to have a motorized wheelchair at school. They made me stay in a manual chair in the home. Because the home wasn't accessible. A motorized chair wouldn't fit through the doors.*

I fell on the floor and I had bruises. The foster family refused to pick me up. I was being told to transfer from a bed to a chair with no brakes. It was four times I was moved between different foster parents. I was getting beat up by a kid hitting me and punching me. From age 13–18, why didn't anybody do anything!? The Children's Aid did nothing to protect me. I feel bad for the little kids

The school tried to complain. *I felt safe at the school. They listened to me. I would have slept there if I could. They knew everything that was going on in foster care. Somebody made a call at school to the advocacy office about everything that was going on. They [the advocacy office] came in. They talked to me. The director from the home says to me…call them back and tell them everything is okay. They wanted me to do that. I felt I would get in trouble if I didn't. I was forced to call the advocacy office back and tell them everything was okay.*

Deep inside I didn't have anybody to tell me whether that was the right thing or the wrong thing to protect me. So my protection doesn't matter to them. They would say I'm making it all up. All the stories I told them about what was happening. They still say that today. Still nobody is listening.

Still fearful today. *Even today I have fears. I still live in an organization where everything has to be locked up. Today, they say that this is my house. Wrong. It's like a group home status. Everything is locked up. The thing I don't like is they say it's my home. All medication, all case binders, money, even tickets to a show have to be locked up in safe keeping. I get my bus pass every month and I don't even bother to give it to them because they would lock it up. There is no explanation why they lock it up. They get mad if I ask. I have no privacy. Nothing is confidential. Not even the manager's office is confidential. No privacy.*

I know it's hard when people take your legal rights away. That worries me every day of my life. They don't tell me what I'm signing. I'm like any other human being on this planet, but because I live in an organization my privacy and rights have to be violated.

I don't know who hires these people. I feel very alone and very trapped. I want people to take a moment and think about how to really just listen to us. I was never heard. And I'm still not heard.

Leaving foster care into developmental services. *After 18, I had my own decision-making rights. Nobody told me I was leaving foster care. The social worker just told me she was going to close my file. I was told I was no longer their concern.*

I didn't even know what to think at that point. I was stuck. Another big agency came in. They apparently help people find housing. I remember the worker not being honest. I was 20 when I finally left foster care.

I wanted to move closer to my first foster parents – who I call my mom and dad. Nobody was listening to me.

Nobody sends complaints to the complaints department because they are scared of what is going to happen. I've wanted to complain but I have been too afraid to send it. The Ministry needs to be more aware of not only foster homes but also in developmental services group homes. Trust me. It's not a pretty picture. The Ministry should show up on a surprise visit to these places more often. They should show up in the foster care but also in the developmental services.

There is no transition. It's just, "Bye – Enjoy your life – Good luck!" Even when I moved here, they were so afraid that me and my roommate were going to get ourselves into trouble. They had a staff following us around 24/7. There was no breathing room whatsoever. We could never pick different programs we wanted to do because there was only one staff. It was scary when I first moved there. I couldn't even see the apartment. Normally you should be able to see the place to see if you like it. They didn't even let me look at the place to see if I liked it. The place is plain white. I don't get to choose what my own place looks like. The staff buy the furniture out of our budget. They make the choices. Now it's gotten worse. No choices. Sometimes staff meet at my apartment and tell me to leave so they can talk to each other while I'm not there.

What I want staff to know today. *I want developmental services staff today to know these things: Get a chance to know the person you are working with. Go for a coffee or go for lunch. To get to really know the person and what they need. There is never a time where me and my staff will go for a walk on a nice day and sit down. Here's what you should know about me and here's what I should know about you.*

They should be asking questions like, "What can I do to make your life easier?" They are here to support us to live our lives. But they overstep. They are trying to act like my mother instead of a staff. I'm always doing something. I'm at home and a staff says, "I think it's time for you to get a part-time job," "you're pacing a lot." I said maybe next summer. They say what they think we need instead of asking us.

I would suggest a booklet for staff on how the person is feeling. When they know foster kids are moving out on their own, spend a couple days and comfort them. Just let them know that you are a good person. Just let them know that somebody else would be there for you. Because I never had that. Just maybe having a photo album, getting pictures together of the last living arrangement and put it in a photo album. I call it living arrangement because that's what it is. It's not a home. Especially when kids are moved all over the goddamned city. A home is something you feel safe in. You come home and you have your teddy bear on your bed. A home is asking what you want for dinner. The sad thing is when a child is feeling upset the staff don't even hug them. You're in this field because you want to help a child, right? [End of Anonymous's Story]

Conclusion

The painful stories of the three youth are clear first-hand statements on how the system has failed youth transitioning out of foster care and into developmental services. As we can see in their stories, backed up with the research, not only did the foster care system leave scars on the youth, but the current developmental services system also has a long way to go to improve services and meet the needs of these "system kids."

Staff we interviewed for this research highlighted that we need more options for people in crisis, such as having more treatments available. For example, there is a need for the creation of more safe beds, more intensive support for short periods of time, so that people can be diverted from the criminal justice system.

More crisis planning is needed, as are protective factors built into developmental services. For example, an option is to build crisis support capacity within group homes so that in the event that something happens suddenly, they will be able to handle it.

Staff stated that if these youth are not well supported then they can potentially end up in the criminal justice system, which costs society as well as these individuals' well-being. As one interviewee stated, "jail is used like foster care for adults as we try to get support as we have no other options because there are large waitlists or no service at all for this cohort." Staff reported that the criminal justice sector is often the last resort. If there was more support for caregivers, and better transition support conducted earlier, then that would significantly reduce the number of these individuals who are ending up in jail. This is only one of the critical issues that needs to be addressed in improving service delivery for these youth.

The face of developmental services is changing before our eyes, with youth transitioning out of foster care, asking for a different kind of service than the sector has known how to deliver. The developmental services sector has major adaptations to make as we learn about the needs of the new population we are serving so that we do not continue to re-victimize these youth. As the three storytellers have outlined in their narratives, there are unique needs that come with having grown up in foster care. Deinstitutionalization is, thankfully, behind us; however, youth leaving foster care bring a whole new world of advocacy and critical human rights work that is calling to be done. Youth like the three telling their stories in this paper are voices unto themselves. They are asking for their rights to be respected, and for their stories to be honoured. They are asking to be listened to.

As one staff interviewed stated: "Agencies… the sector is not equipped to service the needs of these TAY." The changes that are needed are needed now, and need to be implemented quickly. We hope these stories serve to remind us of the importance of listening, of changing how we are delivering service and most importantly, of bringing well deserved respect to these youth who have already proved their resilience over and over, and deserve better.

Key Messages From This Article

People with disabilities. Transition aged youth labelled with intellectual disabilities who have grown up in foster care deserve to be treated with respect. The respect needs to be there in foster care, and also in developmental services.

Professionals. Transition aged youth labelled with intellectual disabilities who have grown up in foster care need stability and kindness to thrive.

Policymakers. Policy to ensure that transition aged youth are given the supports they need to have success in life when leaving foster care and entering developmental service is very important.

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