VIRTUAL
2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Session 15918
Innovations to Increase Engagement with HIV Services among Adolescents and Young Adults Living with HIV

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Disclosures

- Natella Rakhmanina, Nara Lee and Olivia Munger are recipients of the following Ryan White awards to Children's National Hospital: District of Columbia (DC) Part A, Part A-MAI, and Part B; Suburban Maryland Part A-MAI, Title IV Part D, DC Regional Early Intervention Services
- Natella Rakhmanina is an active member of:
  - US Department of Health and Human Services Panel on the Pediatric Antiretroviral Therapy and Management Guidelines at the Office of AIDS Research Advisory Council in National Institutes of Health
  - Washington DC Regional Planning Commission on Health and HIV, Washington, DC, appointed by Mayor Muriel Browser
  - Pediatric Advisory Working Group at the World Health Organization
- Presentation will not discuss an unapproved use of any drugs or devices.
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- Commercial support was not received for this activity.

Learning Outcomes

At the conclusion of this activity, participants will be able to:

1. Identify barriers to engagement in care of adolescents and young adults living with HIV (AYALHIV) in the USA
2. Utilize innovative approaches to effectively support transition along the continuum of care among AYALHIV
3. Apply creative interventions to engage adolescents and young adults and their support networks and communities

Setting up Youth Specific Targets for Quality Management of HIV Program

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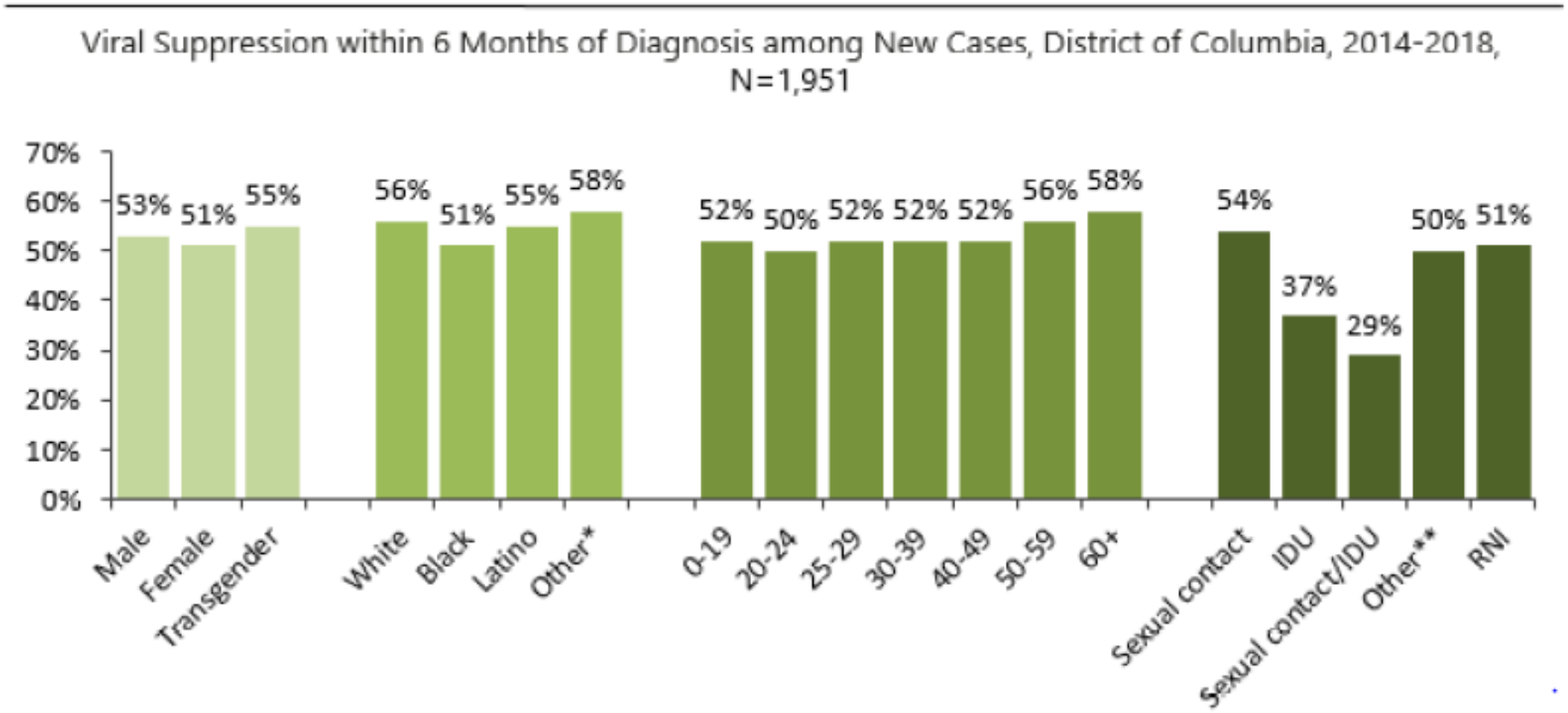
HIV Cascade among AYALHIV in the USA

1 in 4 of all new HIV infections is among youth aged 13- 24 years

~60% of youth with HIV do not know their status!

CDC, 2017

Viral Suppression among AYALHIV in Washington, USA

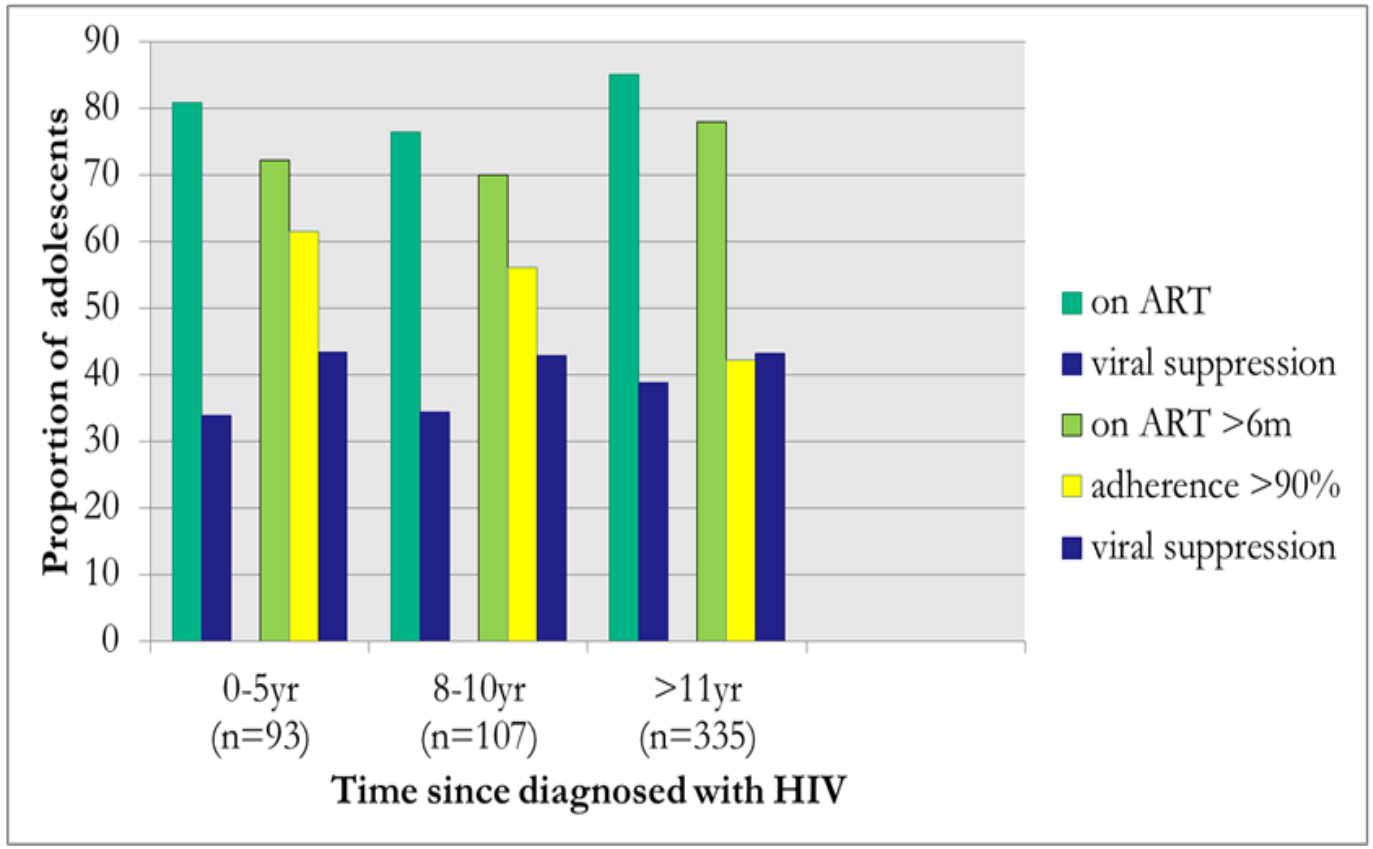


Annual Epidemiology & Surveillance Report: Data Through December 2018. DC DOH; HIV/AIDS, Hepatitis, STD, & TB Administration, 2019.

Adherence in AYALHIV

649 perinatally infected youth (PIY) and 1547 behaviorally infected youth (BIY), 20 Adolescent Medicine Trials Network (ATN) for HIV/AIDS Intervention Sites, 2009-2012

Kahuna, JAIDS, 2015



- Low proportion of virally suppressed PIY across all age cohort (Graph)
- 82.4% of PIY and 49.1% of BIY on ART
- Only 37% of PIY and 27% of BIY were virally suppressed
- Viral suppression rates did not vary as a function of time since HIV diagnosis in either group
- Consistent HIV care and lack of substance abuse were significant correlates of ART use among PIY
- Older age, heterosexuality, employment, and education - significantly related to ART use in BIY

Customer-Level Challenges among AYALHIV

Multiple Transitions

- HIV status disclosure
- Physical development
- Physiological changes
- Sexual onset
- Cultural/religious transformation
- Social integration
- Behavioral adaptations
- Emotional liability
- Educational status
- Psychological maturation
- Financial independence

Multiple Adherence Barriers

- Stigma – self-perceived and external
- Disclosure to friends/peers/partners
- Peer pressure
- Risk taking behaviors
- Substance abuse
- Socioemotional liability
- Mental health issues
- Limited economic independence
- Access to independent transportation
- Multiple life priorities
- Irrelevance of long-term consequences

Zanoni BC et al., 2014

Models of Care with Higher Engagement in Care among AYALHIV

- Study evaluated a linkage to care and engagement in care initiative for HIV-positive adolescents in 15 USA-based clinics
- Only 62.1% (1043/1679) of adolescents were linked and engaged in care
- Model A - real time data shared with outreach workers working directly with consumers - most efficient
- Overall, *data sharing mo*del and *outreach worker effectiveness* were both significantly associated with better engagement in care
- Clinics *serving adolescent and pediatric customers* and those that *focused on HIV only* were more successful in engaging adolescents than those that were adolescent only

Philibin MM et al, 2014

Improving Continuum of Care for AYALHIV in the USA

- **Interventions and programs, both independent and collaborative, to improve outcomes**
- Community- and structural-level interventions to improve outcomes
- Strategies to address evolving healthcare financing challenges
- Evaluation of long-acting antiretroviral therapy for treatment
- Risk-reduction interventions
- **Interventions to promote care engagement and adherence to antiretroviral medications**
- **Integrated treatment approaches (psychological, medical, and ancillary services studies)**

Lee S, et al. 2019

AYALHIV in Care

Our Clinic Population at a Glance

- 69.5% >12 years of age (~160 clients)
- 48% females, 77% perinatally infected
- 30% African immigrants
- 10% international adoptees
- 10% off antiretroviral treatment (ART)
  - Non-adherent
  - Elite controllers
- 40% living with non-biological parent as a caregiver
- 75% virologic suppression rate among AYALHIV on ART

Our Model of Care at a Glance

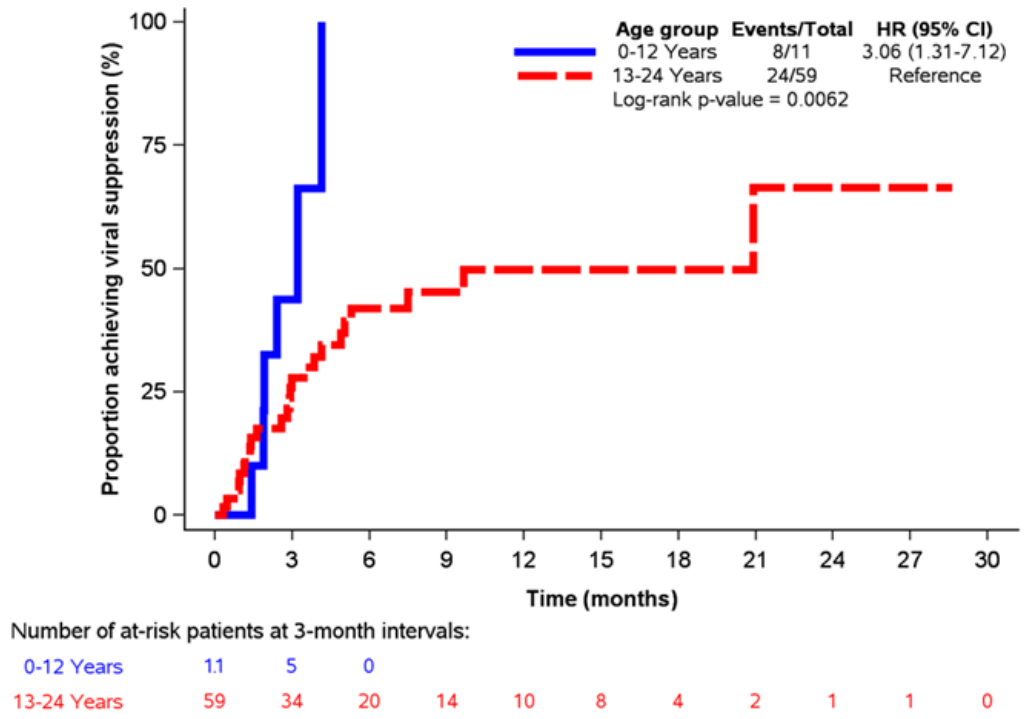
- Multidisciplinary team of HIV providers
  - Medical doctors, nurse practitioners, registered nurse
  - Medical nutritionist/adherence supporter
  - Pediatric/Adolescent psychologists
  - Case managers/patient navigators
- Weekly clinic review meetings
- Monthly quality management meetings
- Bi-annual team retreats
- Active collaboration with the community (23 MOUs)
- Active engagement with three regional Departments of Health (MD, VA and DC)

Virologic Suppression among Treatment-Experienced Customers

- More than half of customers with detectable viremia at baseline did not achieve viral suppression on integrase inhibitor-based ART
- Among non-suppressed customers at baseline, customers <13 (vs. 13-24) years old were more likely to achieve VS (p=0.0062).

Levy ME et al, 2020

Kaplan-Meier curves for achieving viral suppression among non-suppressed patients (n=70)



Caring for AYALHIV

What have we learned:

- Success comes with multiple team member efforts
- Be prepared for multiple stops and restarts
- Ongoing communications within the team and with customers is key
- Always take time to listen, and get used not to always being heard
- Your commitment to the customer will pay off!
- Help caregivers to cope and find their balance as AYALHIV change their priorities and needs

"Do not judge me by my success, judge me by how many times I fell down and got up again"

Nelson Mandela

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Let us Share the Meal!

Using Cooking Classes and Nutritional Education as a Youth Empowerment and Peer Support Platform

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Why Nutrition Services?

- Good nutrition is an important part of leading a healthy lifestyle
- Good nutrition represents a significant component of HIV care
  - Supports overall health
  - Helps maintain the immune system
  - Supports healthy weight
  - Allows to better absorb some antiretroviral medicines (ARVs)
- Both malnutrition and obesity have been associated with long-term related co-morbidities in people living with HIV:
  - Cardiovascular disease
  - Chronic inflammation
  - Insulin resistance
  - Dyslipidemia

Hazra et al., (2010); Hulgan, et al., 2018; Non, et al., (2017); Nou, et al., (2016)

Multiple Resources on Healthy Nutrition Nationwide

- Health Resources and Services Administration (HRSA): *Guide for HIV/AIDS Clinical Care: Nutrition*
- CDC: *Healthy Living with HIV*
- U.S. Department of Veterans Affairs: *Diet and Nutrition for People with HIV*
- FDA: *Food Safety for People with HIV/AIDS*
- USDA: *ChooseMyPlate.gov*

Nutrition Related Risks

- Pediatric and adolescent obesity rates are at highest level:
  - National pediatric rates - 18.5%
  - Children's National Hospital Ryan White Services - 16.7%
  - Pediatric HIV+ cohort in FL - 12%
- Pediatric fruit and vegetable intake is inadequate in the USA, particularly among socially and economically disadvantaged minority AYALHIV
- Home cooking has further declined over last decade
- Decrease in parental transfer of cooking skills to children
- Majority of the delivered meals and meals away from home are higher in salt and fat content
- Adolescents and young adults lack food-related skills, which can be predictive of poor nutrition habits in the future

Arbeitman, et al., 2014; Centers for Disease Control and Prevention, 2019; Hasan et al., 2019; Jacobson et al., 2011; Nelson, et al., 2013; Saksena, et al., 2018; Taillie, 2018

Nutrition Services for AYALHIV

We provide wide array of ***nutritional support services*** including:

- Nutrition assessment
- High-dose vitamin D quality management project
- Food insecurity screening and referrals
- **In-clinic produce and food distribution**
- **Cooking classes for customers and siblings**
- **Collaboration and coordination of nutritional activities with AYALHIV Peer Group and Parent Advisory Council (PAC)**

Nutrition Services

In-clinic produce distribution

Non-perishable food distribution

Benefits of Cooking Classes

- Evidence supports positive effect of cooking class on anthropometric outcomes and/or diet quality
- Other positive outcomes of cooking classes include:
  - Increases in cooking skills/knowledge
  - Improved food safety behaviors
  - Improved behavioral intention
  - Increased perceived cooking ability
- Most frequent and most important for AYALHIV outcome is ***increased self-efficacy from experiential hands-on learning***
- Food exposure also increase acceptance of good nutrition and self-efficacy through viewing, smelling, handling, and tasting new combinations
- Hasan et al., 2019; Kuroko, et al., 2020; Nelson, et al., 2013

Cooking Classes for AYALHIV

- ***Goals*** of cooking classes for AYALHIV:
  - Exposure to new foods
  - Learning cooking techniques
  - Building sense of community
  - Increased self-confidence
- Launched in 2018 & holding one cooking class per month
- Partnered with mental health for collaborative approach
  - Biannual special cooking lessons for young adult peer support group
  - Monthly teen group: “HerStory” Summer Series, 2019; “Super Saturdays”, 2020
- Take home groceries assembled to use/recreate recipes

Cooking Class Lesson Plan

- Duration - one hour
- Held after peer support group – relaxation time
- PAC can run simultaneously
- 5 minute lesson and recipe review
- 40 minutes of joint cooking
- 15 minutes of eating and clean up
- New recipe every class:
  - ✓*Fish tacos, chicken tikka masala, jambalaya*
  - ✓*Teriyaki meatballs, meat loaf, pot stickers*
  - ✓*Homemade noodles, Pizza, Quesadillas*
  - ✓*Breakfast*

Cooking Classes – Sessions and Attendance

	3/2018 – 2/2019	3/2019 – 2/2020
Total Attendees	57	44
RW Eligible Children	33	39
# of classes held	14	13

Cooking Class in Action

Super Saturday

- Attendance
  - 10 “regulars,” 80% female, ages 8 -18 years
  - Due to peer group partnership, participants must be disclosed
- Timing
  - Saturdays 10:00 – 12:00, 1 hour peer support, 1 hour cooking class
- Location
  - Children’s National Hospital Black Bear Kitchen
- Set up
  - Ideally each participant has their own station and makes their own recipe

Cooking Class Survey Results

Question	Average Score (1 – 5)
I feel confident that I can prepare a recipe on my own at home	4.5
I learned something new about cooking and/or nutrition at today's class	4.9
I believe that the lesson today was relevant to me	4.5
The class taught me to make healthier food choices	4.5
I would be interested in coming to another cooking class	4.9

Parent Advisory Council (PAC)

- Launched in January 2019
- Run in collaboration with case managers
- 8 meetings since held, most simultaneously with cooking classes
- 3-4 parents per group - max attendance was 7
- Started as PAC, but naturally turned into more and functions also as a Parent Support Group
- Discussed topics include:
  - Transition to adult care
  - Disclosure
  - Adherence support
  - Scientific/treatment updates

Alternate Set Up

- Recreation center/library
- Room with a sink and outlets
- $2,500 start up + room rental
- $200 per class (does not include take home groceries)
- 6-8 tables/families
- COVID Lockdown response – family packages:
  - Mental health - art supplies
  - Parent/AYA support – lotions/self-care products
  - Nutritional support - cook book, $50 grocery gift card

Useful Tips

- Ages ≥9 years are able to use a chef's knife and cook with supervision
  - If including parents, encourage them not to do the cooking!
  - One adult per 2-3 teens
- Younger children can make recipes that don't involve cooking
- Testing recipes ahead of time is important!
- Allow teens to mess up and have fun!
- Keep a first aid kit on hand!
- Encourage participants to clean up after themselves and have staff help/set up role models
- Include evaluation survey and wish list

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Uber Me!

Innovative Solutions to Improve Youth Retention in Care and Support Services

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Importance of Transportation to Engagement and Retention in Care

- Transportation barriers have been shown to negatively affect healthcare access (Sayed et al, 2013):
  - Long wait times for public transportation
  - Inaccessibility to vehicle or transportation
  - Cost of public transportation
- Transportation barriers are more significant among adolescents and young adults living with HIV (AYALHIV) (Philbin et al, 2014)
  - **Barrier** "We're dealing with youth who have no jobs so you can't even buy a bus pass, and if you need a bus pass it needs to be mailed to you so you have to get in contact with your case manager at least two weeks before your appointment." Site T
  - **Solution** "I think the biggest thing is the taxi, being able to taxi a kid from 40 miles away to get to a doctor's appointment just to make sure that he gets here." Site S

Rideshare Services Emerging Data

- Early results show that rideshare services may decrease average wait times and average ride costs (Powers et al, 2016)
  - ~$2.7 billion spent on non-emergency medical transportation annually
    - Wait times are long (sometimes ~60 min) and drivers often no-show
  - Lyft launched "Concierge" in 2016, partnering with many healthcare organizations for medical transport
  - Uber Health launched in 2018, working with healthcare organizations for medical transportation
  - Average wait times have decreased by 30% (12.52 to 8.77 minutes)
  - Average per-ride costs have been reduced by 32.4% ($31.54 to $21.32)
- Study with refugee women demonstrated lower no-show rate (6%) in women using rideshare *vs* women who used own transportation to attend clinic (30%, $p<0.0001$) (Vais et al, 2020)
  - Boston Medical Center's Refugee Women's Health Clinic (Jun 2018 – Feb 2019)
  - All women with gynecologic visits reporting transportation difficulties were offered rides
  - 31/102 women reported transportation insecurity and received rides

Rideshare Services Emerging Data

- University of Pennsylvania Health System showed no difference in attendance at primary care attendance with rideshare services (Chaiyachati et al, 2018)
  - 786 Medicaid beneficiaries in West Philadelphia, 72% women, mean age 46 years
  - Similar rates of missed appointments for those who used rideshare (36.5%) vs those who did not use rideshare (36.7%, p=0.96)
  - But general uptake for rideshare was low (only 57/288 or 19.8%)
- Data are lacking on the impact of Rideshare use on subspecialty HIV clinic/care attendance
- To date, no data are published on how Rideshare services affect customer health outcomes

Rideshare Services
Children's National Hospital

- Launched in 2018 using hospital Uber Health account
- Supported by Ryan White transportation funds
- Thorough review of customer's needs, including:
  - Ryan White eligibility
  - Distance to residence/work/school
  - Availability of transportation including for previous visits
  - Facilitators/barriers to care
- Initially launched to support medical appointments only
- Quickly identified additional transportation needs:
  - Mental Health appointments
  - Peer Support groups/Cooking classes

Rideshare Services
Standard Operating Procedures

- Uber Health rides scheduled every Friday for the following week appointments:
- Case manager must evaluate any other transportation options for customer/family prior to utilizing Uber Health.
- If deemed Rideshare eligible, case manager gathers the following information:
  - Customer name
  - Appointment date & time
  - Address of pick-up
  - Cell phone number/email address of customer and/or guardian
  - Pick-up time (according to Google Maps estimate)
- Reminder call made to customer on day of Rideshare service
- Initial text message received by customer when ride is scheduled and a second text on the day of their ride indicating: driver's name, car type/color & license plate #
- Customer is asked to check with the driver prior to entering the car
- Customer is asked to contact case manager if they need immediate assistance or have any problems with the ride

Rideshare Services
Customer Communications

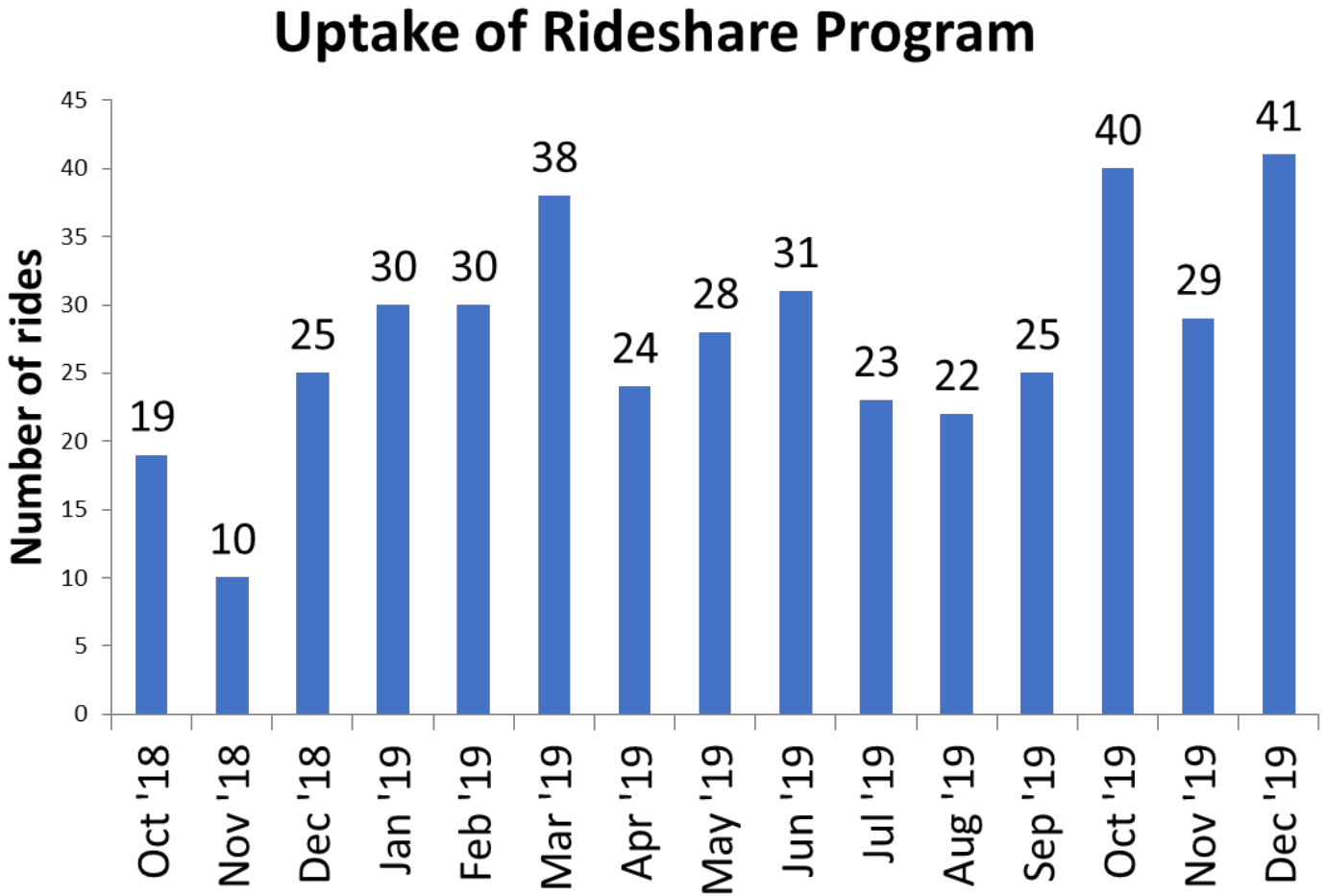
- **Handling no-shows**
  - If a customer has ***two consecutive no-shows,*** they are temporarily suspended for 6 months using Rideshare due to incurred cancellation costs ($5 cancellation fee with Uber Health)
- **Communicating Customer's responsibilities:**
  - Open communication with their case manager
  - 24 hours cancellation notice
  - Must have a working cell phone/email address for accessibility purposes in order to receive text message/Rideshare notifications
  - Observe safety precautions when using Rideshare

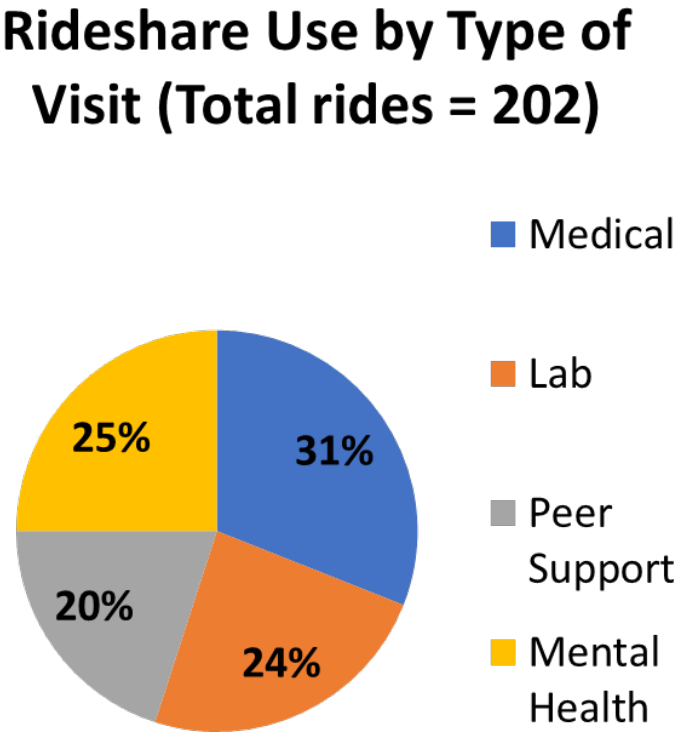
Rideshare Services Data Tracking

State (RW Insurance Juris-diction	Clinic (SIS/ Burge	Next Appt. Date	Pick up Address	Pick up time	Special Instructio	Ride scheduled (Y/N	Appt. Kept (x)	Appt. Missed ($5 fe	Fare To CNM	Fare To Hom	Total Cost Round Tr	Comment
MD	SIS	3/2/2020		9:30 AM	Burgess Appointment	Y	X		$ 22.46	$ 32.29	$ 54.75	
DC	SIS	3/2/2020		2:45 PM	SIS Appointment	Y	X		$ 15.58	$ 14.38	$ 29.96	
VA	EIS	3/2/2020		3:30 PM	PrEP/EIS	Y	X		$ 26.66	$ 25.59	$ 52.25	PO baby who is high risk
MD	SIS	3/3/2020		8:30 AM	SIS Appointment	Y	X		$ 19.34	$ 19.92	$ 39.26	Re-engaging in care after being closed out (LTC - over 6 months)
DC	SIS	3/4/2020		10:00 AM	SIS Appointment	Y	X		$ 9.37	$ 7.98	$ 17.35	Coming with her baby (has her own car seat)
MD	SIS	3/4/2020		1:10 PM	Mental Health	Y	X		$ 29.25	$ 66.26	$ 95.51	
DC	SIS	3/5/2020		9:15 AM	Mental Health	Y	X		$ 20.90	n/a	$ 20.90	
MD	SIS	3/5/2020		12:00 PM	Mental Health	Y	X		$ 38.82	n/a	$ 38.82	
MD	SIS	3/9/2020		1:57 PM	MCM	Y	X		$ 15.99	n/a	$ 15.99	Transition to Adult ID care - MCM appointment & Coodrination of Adult Neph. Appt. also.
MD	SIS	3/11/2020		8:00 AM	SIS Appointment	Y	X		$ 34.34	$ 28.81	$ 63.15	
MD	SIS	3/11/2020		9:15 AM	SIS Appointment	Y		$ 9.40	$ -	$ -	$ 9.40	Patient no-showed to his appt. Told SW that he gave her the wrong address and was driven by his mother and 1 hour late to his appt.

Case managers and data manager maintain Rideshare database to ensure all pertinent information is tracked for each customer.

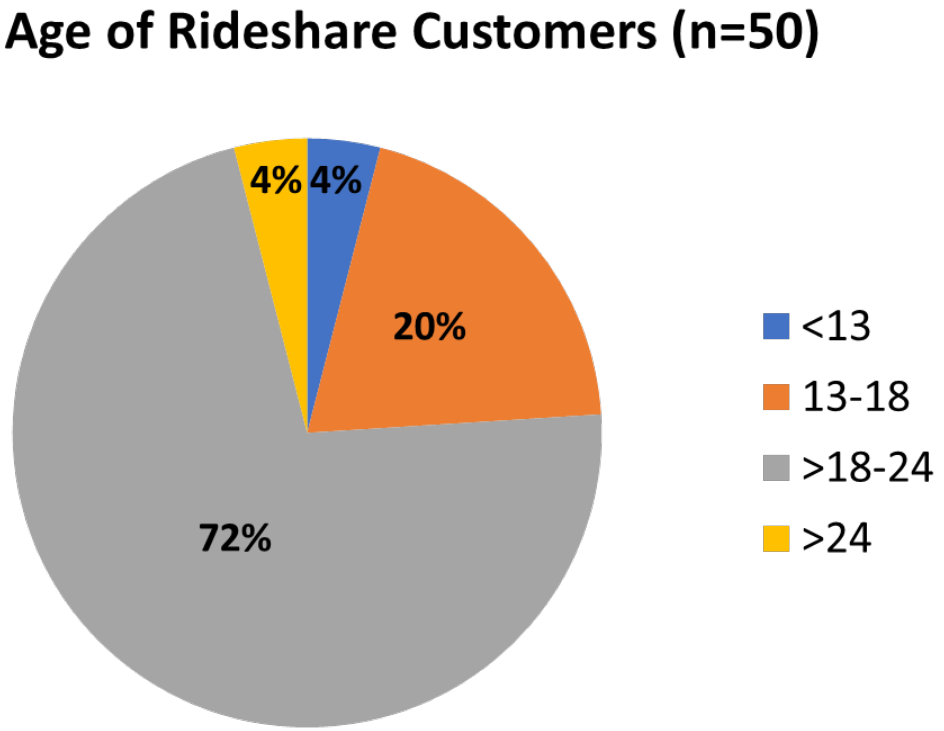
Rideshare Services Customer Uptake





Rideshare Services Program Evaluation

- Prospective cohort analysis of AYALHIV in care (including those who have not used Rideshare) and their caregivers
- Institutional Ethics Committee approved
- Conducted during October 2018-Dec 2019
- Anonymous voluntary surveys were administered to evaluate satisfaction (Likert scale) and likelihood of using Rideshare in the future
- Demographics (gender, age, race) were collected
- Descriptive statistics were used for analysis



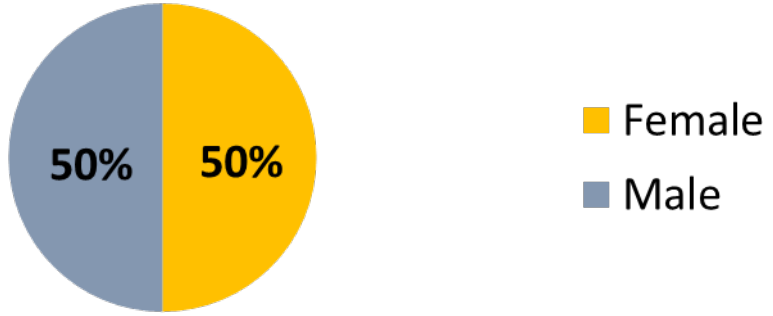
Rideshare Services Customers Survey

Surveyed Rideshare users (90% Black):

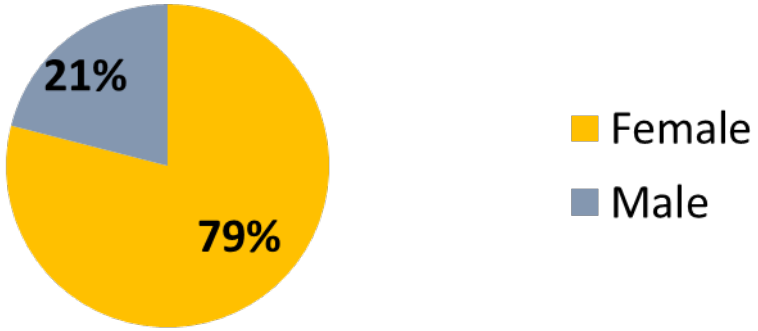
- 50 AYALHIV - median age 19 years
- 14 caregivers - median age 42.5 years
- 42.8% of caregivers used Rideshare multiple times (2-3 times) in the previous 12 months
- Caregiver perspective:

"Uber/Lyft is very helpful for me. I often have to leave work from one part of town to get my teen that's in another part of town, which takes about an hour. Then we have to drive to clinic which can take more time. When an Uber/Lyft can pick my teen up, that is very helpful".

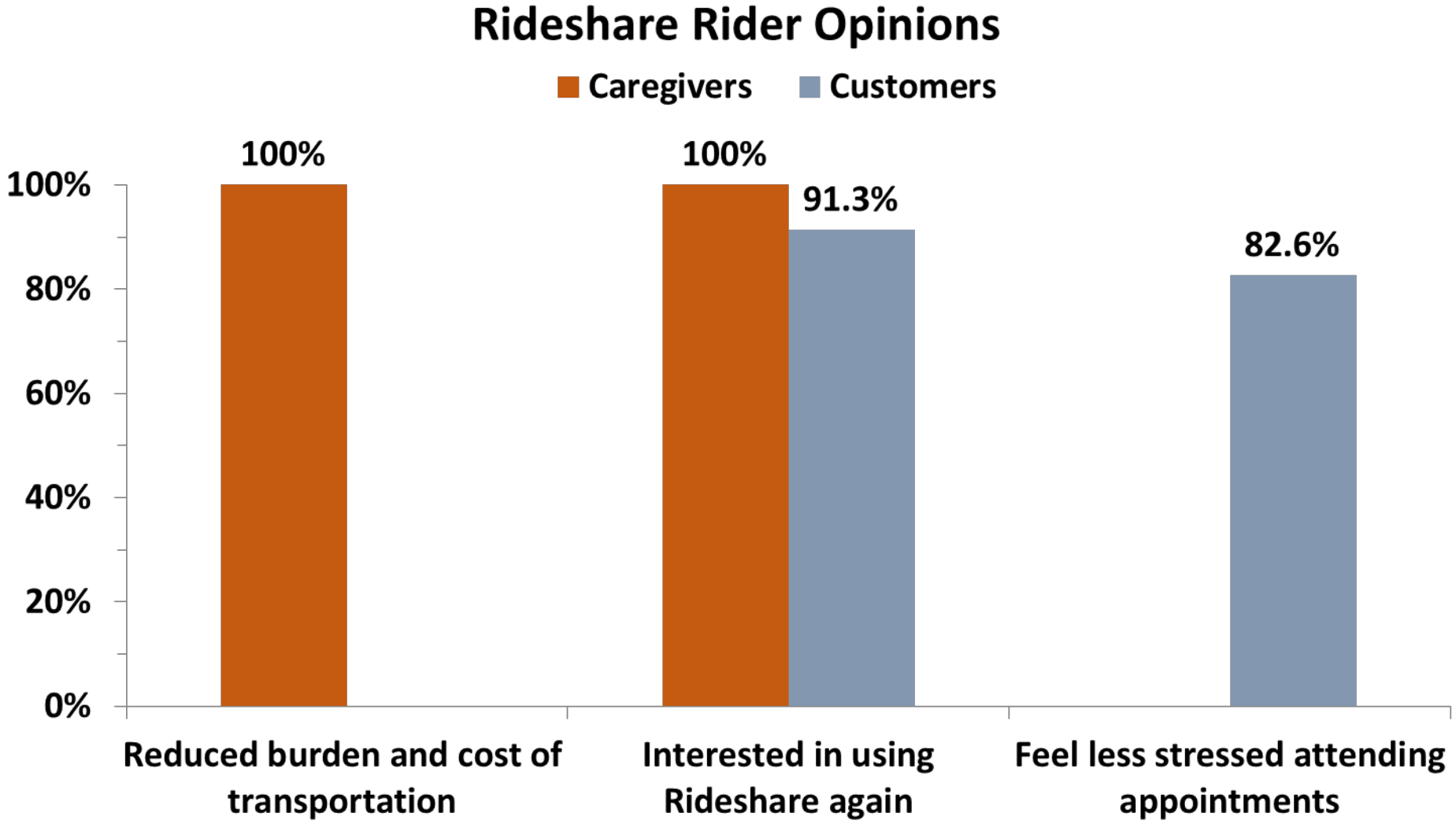
Gender of Customers who used Rideshare



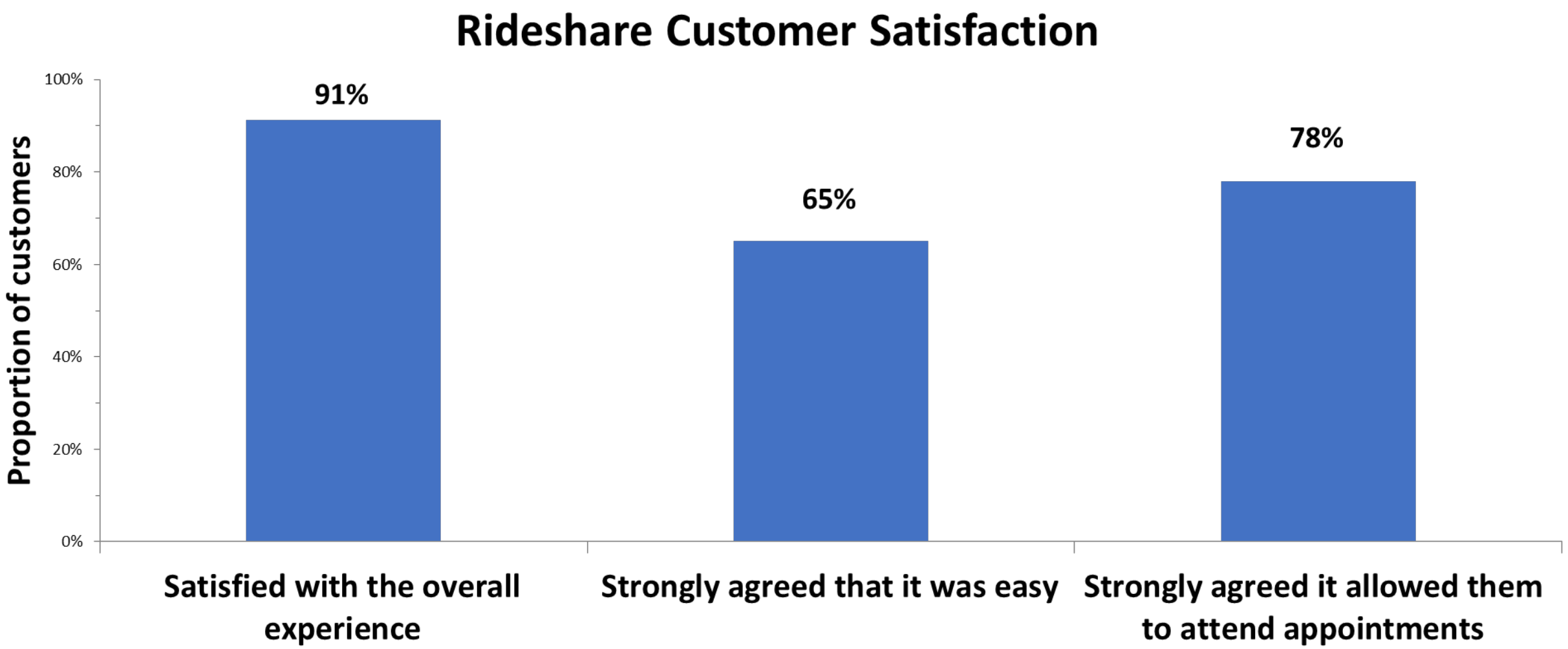
Caregivers who used Rideshare



Rideshare Services User Opinions

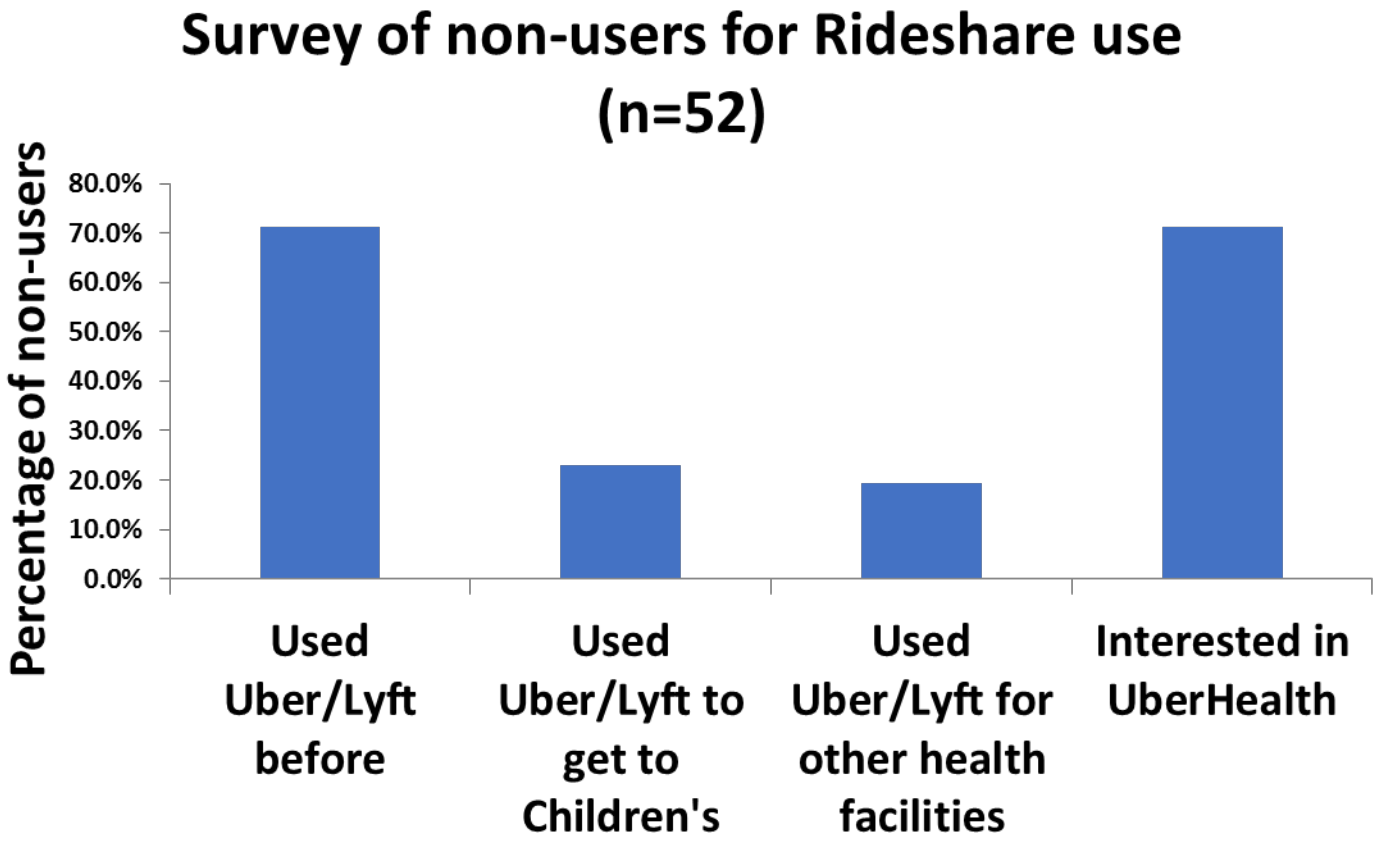


Rideshare Services Customer Satisfaction



Rideshare Services Interest among Non-Users

- **Goal:** to evaluate experience and interest in using Rideshare in the future for care visits among non-users
- Administered to those who have never used Rideshare to evaluate likelihood of using in the future
- AYALHIV comments:
  - *"My mom drives me but as an adult I might say yes to Uber"*
  - *"It would be easier to get to my appointment"*
- Caregiver comments:
  - *"Put it in place for all, a lot of people would benefit"*
  - *"Providing Uber reduces burden of parking"*



Rideshare Services Conclusions

- Rideshare program is associated with high levels of satisfaction and will likely be used again by AYALHIV and their caregivers
- Rideshare use is helpful to support a wide array of AYALHIV care needs including: medical and mental health appointments, peer support groups, and other psychosocial interventions
- Establishing Standard Operating Procedures, customer communication tools, and monitoring and evaluation of the program is crucially important
- An ongoing study is underway to evaluate the cost effectiveness and impact of the Rideshare program on treatment outcomes among AYALHIV

References

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VIRTUAL
2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT
30 YEARS

Young and Lost in Transition

Navigating Transitions in HIV Care

Nara Lee, LICSW
Social Services Manager
HIV Services
Childrens National Hospital
Washington, DC, USA

Transition of Care

- Transition of care involves the engagement of multiple supporters, including, adolescents and young adults, their treatment supporters (e.g., caregivers), various providers, partners, peers, and others.
- Transition process, while observing general principle, is highly individual and needs to tailor to unique customer needs
- Barriers to transition exist on multiple levels – from facility and structural barriers to individual barriers and peer pressure
- The **goal** of successful transition is to sustain and improve clinical care and related outcomes and wellbeing of the AYALHIV

Transition of Care Settings and Outcomes

- ~50% of youth living with HIV who "successfully transitioned" were retained in adult care after one year
- AYALHIV frequently have worse outcomes of HIV disease compared to the adults in the setting of adult healthcare
- ~25,000 HIV-infected youth are scheduled to transition in the next decade

Cervia, JS et al, 2013, Ryscavage P etal, 2016

TABLE 1. ADOLESCENT AND ADULT CLINIC STAFF DESCRIPTIVE STATISTICS

Characteristics and roles	*Adolescent clinic,* n *(%)*	*Adult clinic,* n *(%)*	*Combined,* n
Gender			
Male	4 (13.3)	6 (21.4)	10
Female	26 (86.7)	22 (78.6)	48
Total	30	28	58
Occupation or role in clinic			
MD or MD/professor	7 (23.3)	11 (39.3)	18
NP	7 (23.3)	2 (7.1)	9
Social worker	8 (26.7)	5 (17.9)	13
Case manager	3 (10.0)	3 (10.7)	6
Linkage to care/ patient coordinator or supervisor	3 (10.0)	4 (14.3)	7
Other	2 (6.7)	3 (10.7)	5
Total	30	28	58
Time worked in clinic			
Years	8 (range 1–25)	9 (range 2–25)	

NP, nurse practitioner.

Philbin MM, et al. 2017

Selected Barriers to Transition among AYALHIV

Accustomed to a pediatric facility multidisciplinary team

Bond with staff and facility formed throughout the years

Disclosure and retelling their story can be traumatizing and painful

History of trauma, mental health issues and/or substance abuse

Stigma – internal and external – in the new settings

Cervia, JS et al, 2013

Customer Testimonials

T.M. – 20 yr. perinatally-infected female (customer since 4 years of age)

"My transition to adult care was not an easy one and I had to do a lot of research to find good doctors who offered evening hours and accepted new customers. Although the internet was around, it was not as easy to use for research and finding out information back in 2006 as it is now. It would have been helpful if I were provided with a list of doctors and centers at least 6 months prior to me aging out of Children's Hospital care. I ended up switching providers two times before I found Mary's Center, which I've been at for the past 5 years."

**Now 34 years old, in a disclosed relationship and finishing up school for early childhood development*

Diverse AYALHIV Customers Facing Transition

Kyle, 23 year old male, self-identifies as man who has sex with men (MSM)

- Diagnosed horizontally acquired HIV at the age of 18 years
- Delayed engagement in care ~6 months after diagnosis
- Main caregiver for biological mother
- Works as a night security guard
- Copes with stigma, trauma and depression by heavy drinking
- Multiple admissions for pancreatitis & other related health issues
- ART adherence suboptimal – underwent multiple changes in the regimen – now on 4th fixed dose formulation
- Latest CD4 cell count = 16 cells/mm^3 ; HIV RNA viral load = 360,000 copies/mL
- Needs to transition to adult healthcare provider before 24th birthday

Diverse AYALHIV Customers Facing Transition

Mindy, 23 years old female, self-identifies as heterosexual female

- Perinatally infected
- Elite controller for a long time , never been on antiretroviral treatment
- Had a difficult time even taking daily vitamins
- Believes in alternative medicines and holistic methods
- Recently filed a court case for a sexual assault incident
- Has great family support from her older sister
- Currently has a job as an administrator in a healthcare clinic
- Latest CD4 cell count = 526 cells/mm^3; HIV RNA viral load = 4,240 copies/mL
- Needs to transition to adult healthcare provider before 24^{th} birthday

Transition Program Components

1. Readiness Assessment – Milestones Program
2. Pre-transition counseling
3. Transition intake
4. Transition planning
5. Implementation and coordination
6. Monitoring and evaluation (M&E)
7. Graduation and closure

Milestones Program Readiness Assessment

- The ***main goal*** of this project is to ensure that customers are self-sufficient and confident in managing their own healthcare & improving adherence by the time they are ready to transition to adult care.
- ***Target Population -*** Ryan White eligible AYALHIV in care:
  - 12-24 years of age
  - Disclosed HIV status
  - No cognitive delays
- ***Pilot trial:*** May 2019- June 2019

Transition Readiness Assessment Questionnaire (TRAQ)

- Validated, customer-centered
- Assesses youths' ability to make appointments, to understand their medications and to develop other skills needed for transition to adult care.
- Transition is not unique to HIV
  - Other health conditions (e.g., diabetes, sickle cell disease, cancer, etc.) face transition in care needs
- Use of this instrument has the potential to improve transition assessment and support and improve health outcomes during healthcare transition for youth with special health care needs.

Patient Name: _____ Date of Birth: ___/___/___ Today's Date ___/___/___ (MRN# _____)

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Social Worker: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes ***their*** skill level. **Check here** if you are a social worker completing this form. ☐

	Never 1	Some of the time 2	Most of the time 3	Always 4
HIV Education & Managing Medications 101 (Milestone 1)				
1. Do you know your medication name/appearance?				
2. Do you what the meaning of CD4 Count and Viral Load?				
3. Do you take medications correctly and on your own (pill-taking plan)?				
Health Management I (Milestone 2)				
4. Do you know the name/location/phone number of your pharmacy?				
5. Do you know the name(s) of your clinic/providers?				
6. Do you know the number(s)/email(s) of your providers?				
7. Do you schedule or assist your guardian with scheduling appointments?				
Health Management II (Milestone 3)				
8. Do you schedule other medical visits?				
9. Do you know how to refill your own prescriptions (calling in, picking up)?				
10. Do you know the name of your insurance provider/carry card with you?				
Pre-Transition (Milestone 4)				
11. Do you schedule all of your medical visits?				
12. Have you chosen an adult provider facility?				
13. Have you scheduled your initial adult facility visit?				
14. Do you know your insurance renewal date?				

Gregory S. et al. Measuring the Transition Readiness of Youth with Special Healthcare Needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire. J. Pediatr. Psychol, 2011

Milestones Program - Readiness Assessment

The Milestones Program was designed considering the biopsychosocial assessment conducted by Case Managers on a periodic basis so the customer does not feel as if they are being categorized.

1) Case Managers complete a baseline assessment for each customer
2) A new TRAQ form is completed on a yearly basis to track the progress of each customer
3) Gaps notated in customer's TRAQ form will influence the type of education needed for the upcoming year.
4) Case Managers share this information with the multidisciplinary team during medical rounds
5) Case Managers supplement customer's TRAQ score in clinical progress notes with mini narratives that may indicate delay or halt the customer's progress such as:
   - Death in the family
   - Bullying issues
   - New relationship

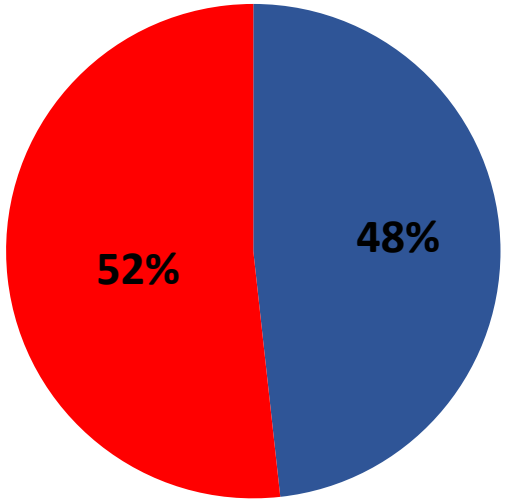
Milestones Program - Data Collection

Patient ID	Last, First
DOB	4/29/1999
Age	21.1
Date of Visit	3/12/2020
HIV Education & Managing Medications 101 (Milestone 1)	
Do you know your medication name/appearance?	4
Do you know the meaning of CD4 Count and Viral Load?	4
Do you take medications correctly and on your own (pill-taking plan)?	4
Health Management I (Milestone 2)	
Do you know the name/location/phone number of your pharmacy?	3
Do you know the name(s) of your clinic/providers?	4
Do you know the number(s)/email(s) of your providers?	2
Do you schedule or assist your guardian with scheduling appointments?	4
Health Management II (Milestone 3)	
Do you schedule other medical visits?	2
Do you know how to refill your own prescriptions (calling in, picking up)?	3
Do you know the name of your insurance provider/carry card with you?	2
Pre-Transition (Milestone 4)	
Do you schedule all of your medical visits?	3
Have you chosen an adult provider facility?	1
Have you scheduled your initial adult facility visit?	1
Do you know your insurance renewal date?	1

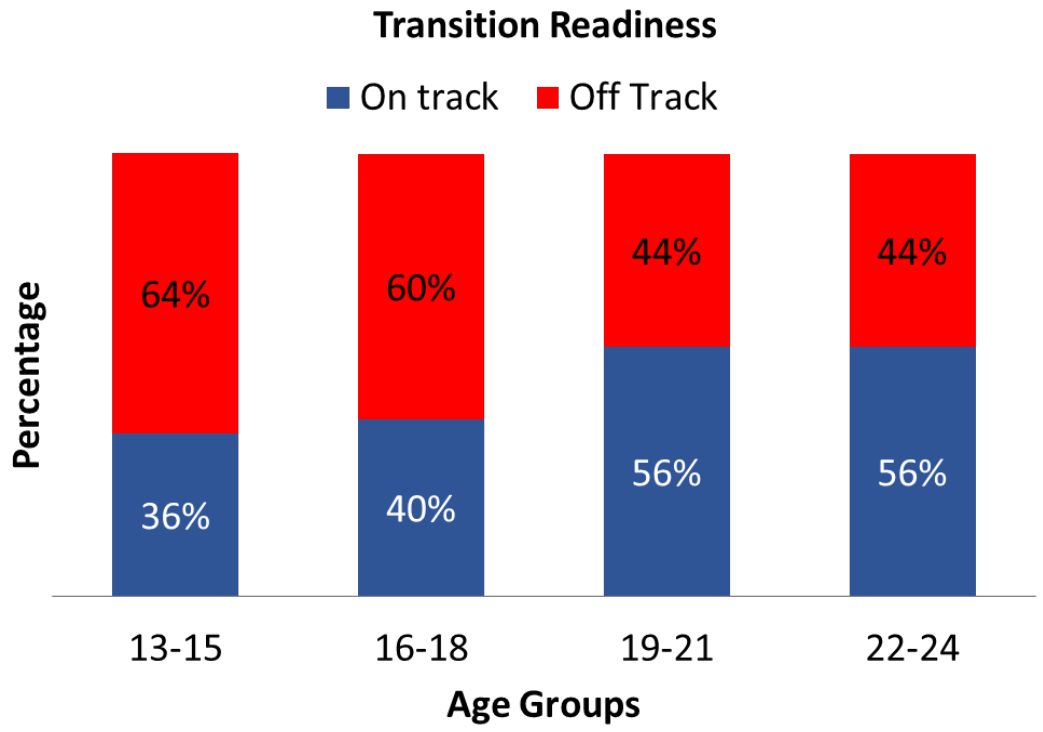
Overall Score	2.71
HIV Education & Managing Medications 101 (Milestone 1) Summary Score	4.00
Health Management I (Milestone 2) Summary Score	3.25
Health Management II (Milestone 3) Summary Score	2.33
Pre-Transition (Milestone 4) Summary Score	1.50

Age Groups	Score Ranges- On Track
13-15	1.5-2.0
16-18	2.0-2.5
19-21	2.5-3.0
22-24	3.0-4.0 ** ≥3.5 - transition ready

Transition Readiness of All Customers:



Milestones Program Baseline Results



- **Goal**: 70% of customers "*on track*" by the age of 18 years through 2020
- Scores recorded in case management files
- Transition readiness included in multidisciplinary team reviews
- Utilizing additional platforms for customer education
- Milestones assessment and transition readiness – part of MH interventions and peer support
- Designing e-mail/texting tips on self-management and transition readiness

Pre-transition Counseling

- A collaborative conversation between Case Manager and customer when customer turns 18 years of age.
- Asking the following questions:

  - What is your understanding of transitioning?
  - What are your feelings towards it?
  - Who would be involved in them transitioning?
  - Who could support them?
  - Describing the Transition process to them.
  - Need to transition by age 24.

Transition Intake

- Case Manager and Customer review transition binder and options that closely match the consumers' wants/needs.
- Discuss the pros/cons of each adult facility.
- A teaching moment for customers because they will realize that not all of their wants/needs are possible, but must decide what is really important.
- Review customer's expectations and how adult facilities function similarly and differently.
- Stakeholders: Consumer, consumer's support system, pediatric clinic, adult clinic, insurance company.

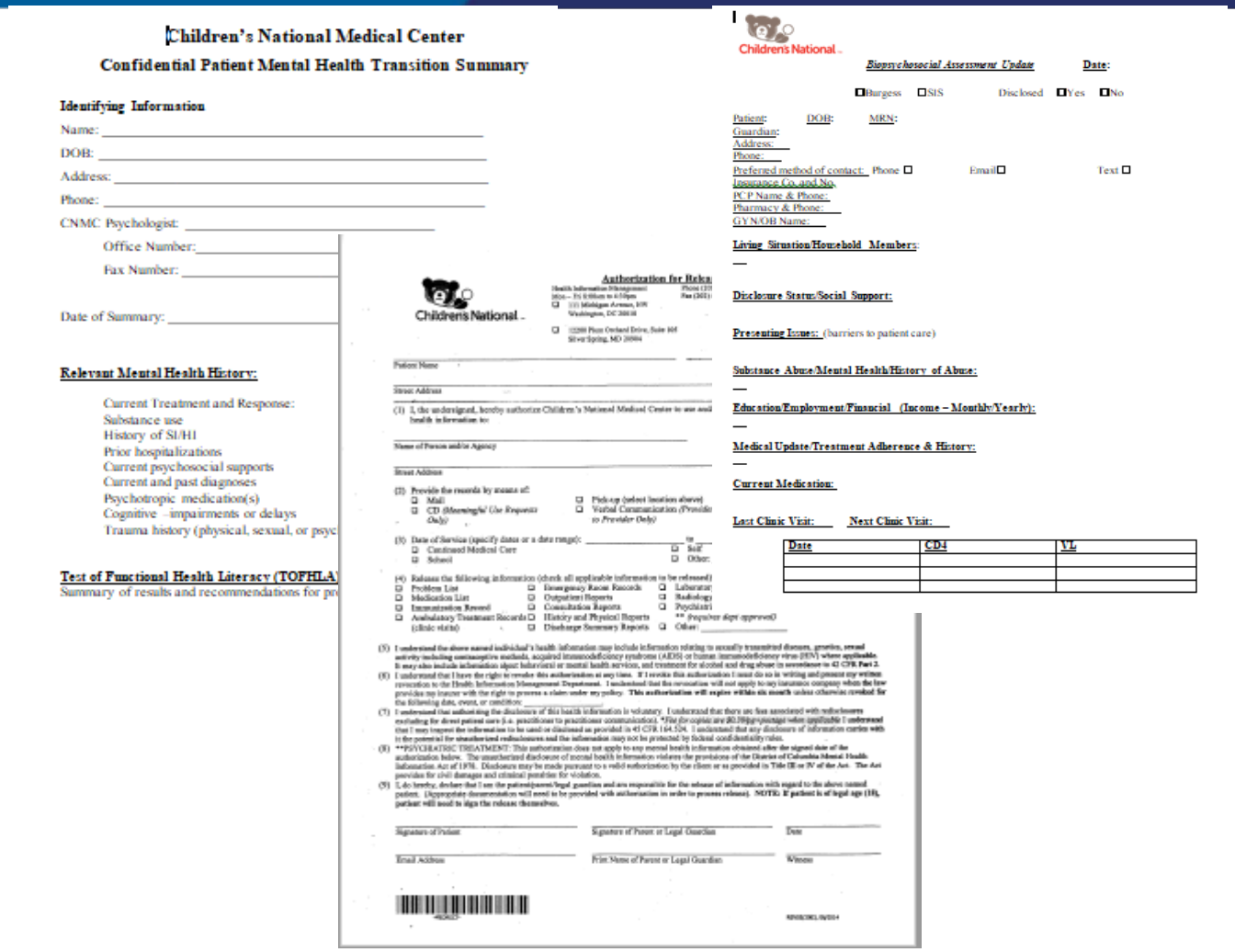
Brainstorming – Choosing an Adult Provider

Wants	Needs
• What would I like to have with my care at an Adult Facility? Think about..... Services offered Convenience List your Wants	• What is necessary for my care at an adult facility? Think about..... Accessibility Support List you Needs

Transition Planning - Transition Package

Transition Packet

- Customer's ID & Insurance card
- Last two sets of lab results
- Last two provider clinic notes
- Immunization records
- Biopsychosocial assessment
- All resistance test results
- Mental Health summary (if applicable)
- Signed Release of Information



Children's National Medical Center

Confidential Patient Mental Health Transition Summary

Identifying Information

Name: _____

DOB: _____

Address: _____

Phone: _____

CNMC Psychologist: _____

Office Number: _____

Fax Number: _____

Date of Summary: _____

Relevant Mental Health History:

Current Treatment and Response:
Substance use
History of SI/HI
Prior hospitalizations
Current psychosocial supports
Current and past diagnoses
Psychotropic medication(s)
Cognitive –impairments or delays
Trauma history (physical, sexual, or psyc

Test of Functional Health Literacy (TOFHLA)
Summary of results and recommendations for pr

Children's National

Authorization for Relea

Patient Name

Street Address

(1) I, the undersigned, hereby authorize Children's National Medical Center to use and health information to:

Name of Person and/or Agency

Street Address

(2) Provide the records by means of:
Mail
CD (Meaningful Use Requests Only)
Pick-up (select location above)
Verbal Communication (Provide to Provider Only)

(3) Date of Service (specify dates or a date range): _____ to _____
Continued Medical Care
School
Staff
Other:

(4) Release the following information (check all applicable information to be released)
Problem List
Medication List
Immunization Record
Ambulatory Treatment Records (clinic visits)
Emergency Room Records
Outpatient Reports
Consultation Reports
History and Physical Reports
Discharge Summary Reports
Laboratori
Radiology
Psychiatri
** Requires dept approval)
Other: _____

(5) I understand the above named individual's health information may include information relating to sexually transmitted diseases, genetics, sexual activity including contraceptive methods, acquired immunodeficiency syndrome (AIDS) or human immunodeficiency virus (HIV) where applicable. It may also include information about behavioral or mental health services, and treatment for alcohol and drug abuse in accordance to 42 CFR Part 2.

(6) I understand that I have the right to revoke this authorization at any time. If I revoke this authorization I must do so in writing and present my written revocation to the Health Information Management Department. I understand that this revocation will not apply to any insurance company when the law provides my insurer with the right to process a claim under my policy. This authorization will expire within six month unless otherwise revoked for the following date, event, or condition: _____

(7) I understand that authorizing the disclosure of this health information is voluntary. I understand that there are fees associated with redisclosure excluding for direct patient care (i.e. practitioner to practitioner communication). *Fee for copies are $0.20/per page when applicable. I understand that I may request the information to be faxed or disclosed as provided in 45 CFR 164.524. I understand that any disclosure of information carries with it the potential for unauthorized redisclosure and the information may not be protected by federal confidentiality rules.

(8) **PSYCHIATRIC TREATMENT: This authorization does not apply to any mental health information obtained after the signed date of the authorization below. The unauthorized disclosure of mental health information violates the provisions of the District of Columbia Mental Health Information Act of 1978. Disclosure may be made pursuant to a valid authorization by the client or as provided in Title IX or IV of the Act. The Act provides for civil damages and criminal penalties for violation.

(9) I, do hereby, declare that I am the patient/parent/legal guardian and am responsible for the release of information with regard to the above named patient. Appropriate documentation will need to be provided with authorization in order to process release). NOTE: If patient is of legal age (18), patient will need to sign the release themselves.

Signature of Patient | Signature of Parent or Legal Guardian | Date

Email Address | Print Name of Parent or Legal Guardian | Witness

Children's National

Biopsychosocial Assessment Update | Date:

Burgess | SIS | Disclosed | Yes | No

Patient: | DOB: | MRN:
Guardian:
Address:
Phone:
Preferred method of contact: Phone | Email | Text
Insurance Co. and No.
PCP Name & Phone:
Pharmacy & Phone:
GYN/OB Name:

Living Situation/Household Members:
—

Disclosure Status/Social Support:

Presenting Issues: (barriers to patient care)

Substance Abuse/Mental Health/History of Abuse:
—

Education/Employment/Financial (Income – Monthly/Yearly):
—

Medical Update/Treatment Adherence & History:
—

Current Medication:

Last Clinic Visit: | Next Clinic Visit:

Date	CD4	VL

Transition Planning - Customer Package

Customer Packet

- Wants/Needs Form
- Taking Charge of your Healthcare
- Tips for Transition
- Farewell letter
- Appointment tool

KEY TIPS FOR TRANSITION

Arrive On time

Being on time to your appointment is very important. Arriving early to your appointment is even better. Plan to arrive at least 15 minutes before your set appointment time to allow proper registration and check-in.

Ask Away

You have the right to know all information related to your care. If you have questions, ask them. You can speak to individuals at the front desk, your provider, nurses, or any person that works at the facility. If they don't have the answer, have them guide you on who to ask.

Write it down

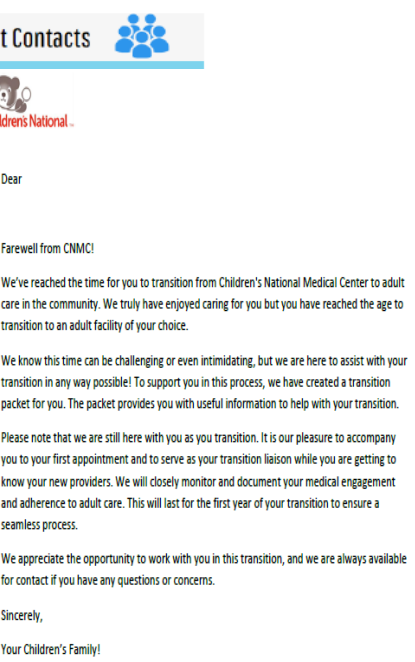
In adult care, you are responsible for knowing information related to your care. Write down your appointment and set reminders. You can put information in your phone or find a way that works best for you!

Confirm or Reschedule

Confirm that you are going to your appointment. If you can't make the set appointment date and time, call the facility to reschedule your appointment. Try and call at least 24 hours in advanced if possible.

Get Contacts

Children's National



Dear

Farewell from CNMC!

We've reached the time for you to transition from Children's National Medical Center to adult care in the community. We truly have enjoyed caring for you but you have reached the age to transition to an adult facility of your choice.

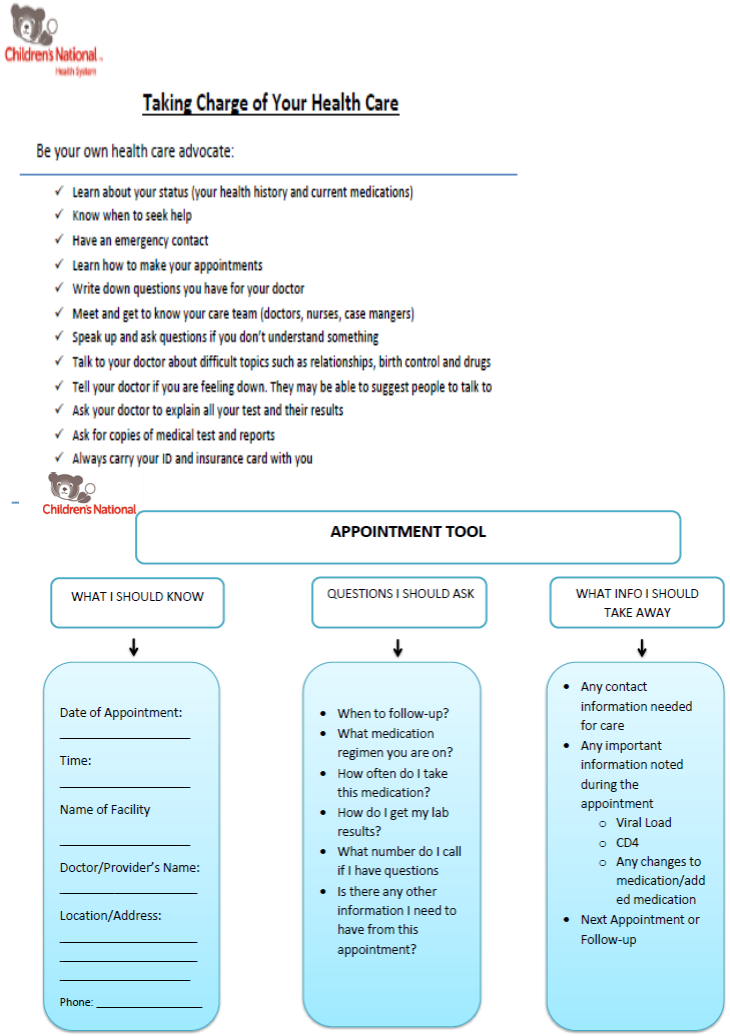
We know this time can be challenging or even intimidating, but we are here to assist with your transition in any way possible! To support you in this process, we have created a transition packet for you. The packet provides you with useful information to help with your transition.

Please note that we are still here with you as you transition. It is our pleasure to accompany you to your first appointment and to serve as your transition liaison while you are getting to know your new providers. We will closely monitor and document your medical engagement and adherence to adult care. This will last for the first year of your transition to ensure a seamless process.

We appreciate the opportunity to work with you in this transition, and we are always available for contact if you have any questions or concerns.

Sincerely,

Your Children's Family!



Children's National

Taking Charge of Your Health Care

Be your own health care advocate:

- ✓ Learn about your status (your health history and current medications)
- ✓ Know when to seek help
- ✓ Have an emergency contact
- ✓ Learn how to make your appointments
- ✓ Write down questions you have for your doctor
- ✓ Meet and get to know your care team (doctors, nurses, case mangers)
- ✓ Speak up and ask questions if you don't understand something
- ✓ Talk to your doctor about difficult topics such as relationships, birth control and drugs
- ✓ Tell your doctor if you are feeling down. They may be able to suggest people to talk to
- ✓ Ask your doctor to explain all your test and their results
- ✓ Ask for copies of medical test and reports
- ✓ Always carry your ID and insurance card with you

Children's National

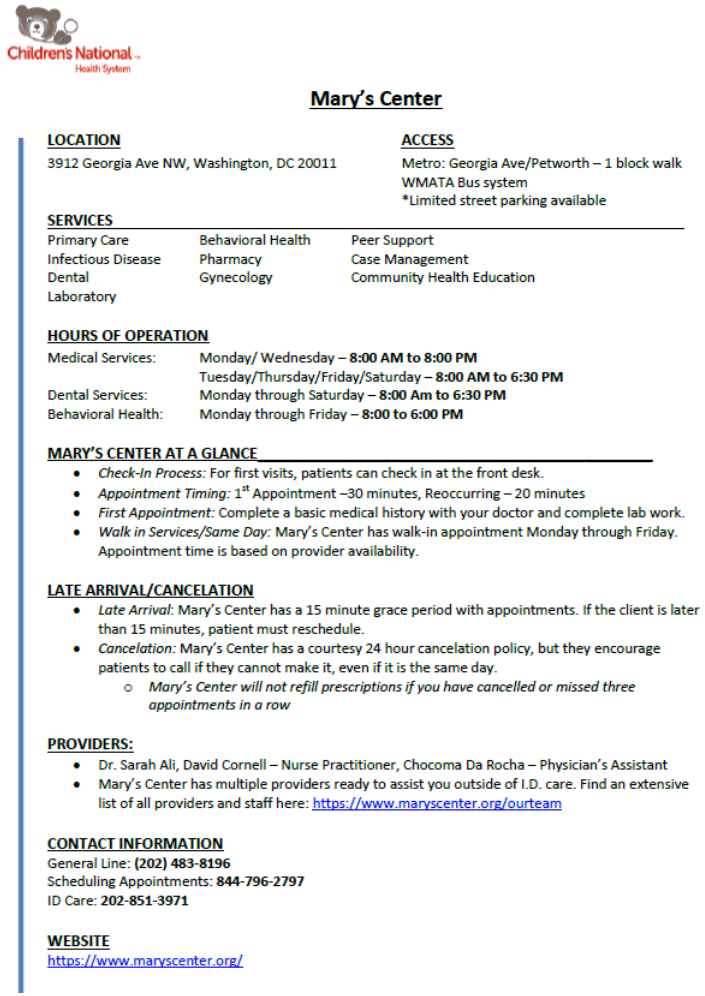
APPOINTMENT TOOL

WHAT I SHOULD KNOW	QUESTIONS I SHOULD ASK	WHAT INFO I SHOULD TAKE AWAY

Date of Appointment: _____
Time: _____
Name of Facility _____
Doctor/Provider's Name: _____
Location/Address: _____
_____
_____
Phone: _____
	• When to follow-up?
	• What medication regimen you are on?
	• How often do I take this medication?
	• How do I get my lab results?
	• What number do I call if I have questions
	• Is there any other information I need to have from this appointment?
		• Any contact information needed for care
		• Any important information noted during the appointment
		  ○ Viral Load
		  ○ CD4
		  ○ Any changes to medication/added medication
		• Next Appointment or Follow-up

Implementation & Coordination

- 12 referral centers to date:
- DC – 8, VA – 1, MD -3
- Transition Binder contains adult facility info:
  - Photos (Outside & Inside)
  - Map of location
  - 1-pager info sheet.
- Customer Care Navigator visited each facility
- Case Managers familiar with all facilities
- Memorandums of Understanding developed with all referral facilities
- Point-of-contacts for referrals and follow up at each facility
- Information update yearly or as needed



Children's National Health System

Mary's Center

LOCATION
3912 Georgia Ave NW, Washington, DC 20011

ACCESS
Metro: Georgia Ave/Petworth – 1 block walk
WMATA Bus system
*Limited street parking available

SERVICES

Primary Care	Behavioral Health	Peer Support
Infectious Disease	Pharmacy	Case Management
Dental	Gynecology	Community Health Education
Laboratory		

HOURS OF OPERATION

Medical Services:	Monday/ Wednesday – **8:00 AM to 8:00 PM**
	Tuesday/Thursday/Friday/Saturday – **8:00 AM to 6:30 PM**
Dental Services:	Monday through Saturday – **8:00 Am to 6:30 PM**
Behavioral Health:	Monday through Friday – **8:00 to 6:00 PM**

MARY'S CENTER AT A GLANCE

- *Check-In Process:* For first visits, patients can check in at the front desk.
- *Appointment Timing:* 1st Appointment –30 minutes, Reoccurring – 20 minutes
- *First Appointment:* Complete a basic medical history with your doctor and complete lab work.
- *Walk in Services/Same Day:* Mary's Center has walk-in appointment Monday through Friday. Appointment time is based on provider availability.

LATE ARRIVAL/CANCELATION

- *Late Arrival:* Mary's Center has a 15 minute grace period with appointments. If the client is later than 15 minutes, patient must reschedule.
- *Cancelation:* Mary's Center has a courtesy 24 hour cancelation policy, but they encourage patients to call if they cannot make it, even if it is the same day.
  - *Mary's Center will not refill prescriptions if you have cancelled or missed three appointments in a row*

PROVIDERS:

- Dr. Sarah Ali, David Cornell – Nurse Practitioner, Chocoma Da Rocha – Physician's Assistant
- Mary's Center has multiple providers ready to assist you outside of I.D. care. Find an extensive list of all providers and staff here: https://www.maryscenter.org/ourteam

CONTACT INFORMATION
General Line: **(202) 483-8196**
Scheduling Appointments: **844-796-2797**
ID Care: **202-851-3971**

WEBSITE
https://www.maryscenter.org/

Monitoring & Evaluation -Visits

Tracking appointments

F	G	H	I	J	K	L	M	N	O
Age	Adult Provider	Acuity Level	XPRES	XPRES (6 month) Due	Last Appt	3 month	6 month	9 month	1year
19.6	Whitman Walker	Intensive	3/11/2019		9/18/2017	3/7/2018	5/16/2018	9/19/2018	1/29/2019
25.4	WHC - Dr. Doshi	Self	11/16/2017	5/1/18	11/16/2017	2/7/2018	6/6/2018	8/1/2018	12/12/2018
25.8	AHF & Kaiser	Self	9/18/2017	3/4/19	9/18/2017	3/19/2018	6/25/2018	10/24/2018	2/12/2019
25.5	Whitman Walker	Basic	12/5/2017	7/19/19	3/15/2018	9/18/2018	11/6/2018	3/7/2019	6/5/2019
22.8	Whitman Walker	Self	11/20/2017	5/1/18	11/20/2017	3/8/2018	n/a	10/12/2018	Feb-19
25.4	Mary's Center	Basic	2/12/2018	3/25/19	2/12/2018	5/4/2018	11/12/2018	12/22/2018	4/1/2019
26.3	Marys' Center	Self	12/13/2017	2/14/19	12/13/2017	2/26/2018	7/11/2018	10/17/2018	1/31/2019
21.8	Dr. John McNeill	Basic	5/15/2018	11/1/18	5/15/2018	n/a	1/3/2019	4/10/2019	
24.0	CCI - Greenbelt	Basic	1/23/2019	7/1/19	1/23/2019				
24.0	TBA	Intensive	12/10/2018	6/1/19	12/10/2018				
24.5	Mary's Center	Basic	3/20/2019	Sep-19	3/20/2019	4/9/2019			

Monitoring & Evaluation - ART, Clinical Outcomes

Tracking ART, Pregnancy, Hospitalization and Co-Morbidities

M	N	O	P	Q	R
Current Medications	**Medication Change (Y/N)**	**Medication Names** (if changed)	**Pregnant (Y/N)**	**Hospitalization (Y/N)**	**New Dx of Co-Morbidity (Y/N)**
Epizicom, Tenofavir and Dolutegravir	Yes	Tivicay, Prezcobix, Rilpivirine	n/a	No	No
Stribild	NO		No	No	No
Triumeq, Truvada	No		n/a	No	No
Triumeq	No		n/a	No	No
Descovy, Prezcobix					
Tivicay,Norvir, Prezista	Yes	Genvoya	No	No	No
Triumeq	No		No	No	No
Descovy & Tivicay			n/a		
NO ARV Meds				No	No
Descovy, Prezcobix			n/a		
Biktarvy					

Monitoring & Evaluation – Laboratory Outcomes

Tracking CD4 cell counts and HIV RNA Viral Load

D	E	F	G	H	I	J	K	L
Last Appt	Last CD4	Last Appt VL	6 month Date	6 month CD4	6 month VL	1 year Date	1 year CD4	1 year VL
9/18/2017	13	255,745	5/16/2018	48	980	1/29/2019	8 (1%)	1,530,000
11/16/2017	1186 (34%)	<20	7/6/2018	1,092	<20	12/12/2018	905	<20
9/18/2017	864 (40%)	194	6/25/2018	946 (39.4%)	<20	10/24/2015	728 (38.2%)	110
3/15/2018	582 (31%)	5,070	12/11/2018	659 (31.4%)	<20	5/29/2019	n/a	<20
11/20/2017	418 (40%)	<20	10/12/2018	484 (44%)	<20			
2/12/2018	820 (36%)	41	11/12/2018	727	<20	Mar-19	678	<20
12/13/2017	1085 (44%)	<20	7/11/2018	857	<20	1/31/2019	926	<20
5/15/2018	1011 (38.9%)	1,810	1/3/2019	946 (47.5%)	100 copies/ml			
1/23/2019	526 (31%)	4,240						
12/12/2018	6 (1%)	193,000						
3/20/2019	944 (19%)	3,720						

Customer Testimonial

M.S. – 24 year old perinatally infected female (customer since birth)

"The staff here have been like a family to me for as long as I can remember. it was definitely a little emotional for me when I outgrew Children's last year. Those staff members who worked closest with me made an extreme impact on my life. I wouldn't change it if I had the option to but when I had to transition, staff made sure I was comfortable and the location of my new clinic was close to me for commute reasons. The very first time I had my appointment, my case manager was right by my side like they always had been. The new, adult clinic seems good and the staff that I have met are extremely helpful and friendly. They work with your schedule and make sure you have a clear understanding in everything they do for you before proceeding. I like it there and I would recommend it for other customers. I am more than grateful for the staff at Children's because they are sincerely support their customers and treat them like family."

***Now working as a admin for a dental office, debating on family planning, starting ARV meds and PrEP for her partner*

Graduation & Closure

Successful Transition if Customer has:

1) Received ≥ 2 labs within first 12 months following transitioning
2) Fully engaged & imprinted with Adult Provider
3) Called the adult provider for info instead of the pediatric clinic.

- Case Manager will follow each transition customer for 12 months after their last pediatric appt. and call the customer & provider ever 3 months to check on their progress, collect data, troubleshoot any issues and write a transition progress note for each adult visit.
- Customer will graduate from the Transition program after their 1 year of Adult care engagement and given a last phone call or letter congratulating them and closure.

Diverse AYALHIV Customers Conclusion

Kyle, 23 year old male, self-identifies as man who has sex with men (MSM)

- Recently hospitalized again for pancreatitis
- Last telehealth appt. at the end of this month just before turning 24 years of age
- Adult provider has been selected
- Case Manager will assist in making 1st adult appointment

Mindy, 24 year old female, self-identified as a heterosexual female

- Selected and attended her first Adult Provider appt. with case manager.
- Transition packet was faxed over prior to appointment.
- Lab work was completed and made her own follow up appt.
- Ready to discuss family planning, starting medications and PrEP for her partner.

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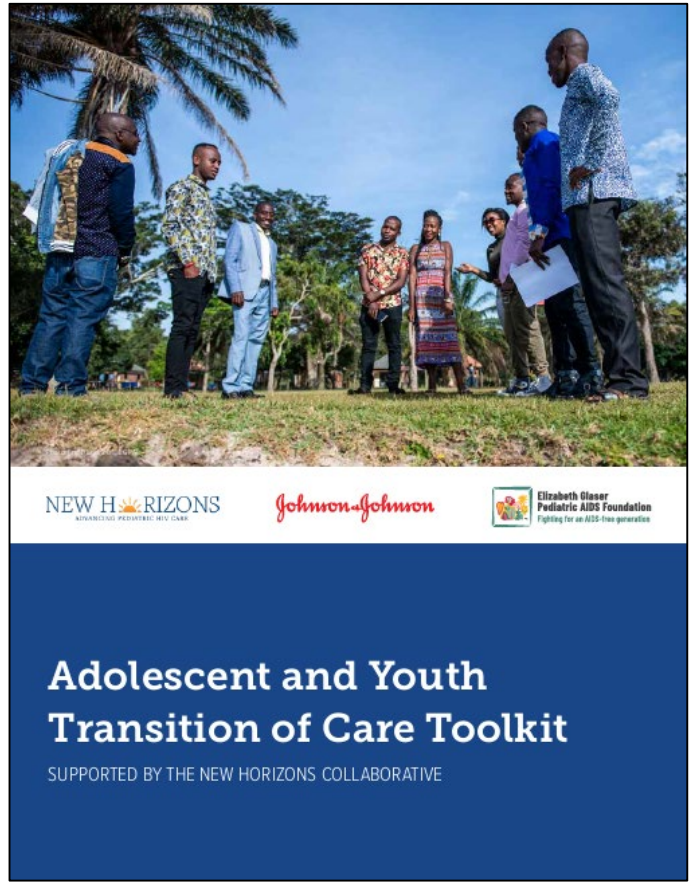

https://www.pedaids.org/resource/adolescent-and-youth-transition-of-care-toolkit/

Questions

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