Effect of Medicaid Expansion on the Crowdfunding Behavior of Transgender Adolescents

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Abstract

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Given the high rates of suicidality among transgender youth and the success of gender affirmation as an intervention for this population, access to medical transition is a crucial issue for the wellbeing of transgender adolescents. While some states in US have increased access to medical transition through mandating the services' inclusion in their Medicaid expansion and tying in policy mandating transition related care in private insurance plans, other states have chosen not to. Along with other factors, this uneven expansion has encouraged transgender adolescents to turn to crowdfunding to raise money for transition related care. In this mixed methods ecological descriptive study I compared trends in states with an Medicaid expansion that included access to medical transition for transgender adolescent to those who did not through the lens of crowdfunding practices to pay for a variety of transition related healthcare costs.

Background

Gender and Adolescents

Individuals who have gender identities different than the sex they they were assigned at birth (i.e transgender people) have existed at all points in history across all geographic locations[1]. However, transgender people have experienced an uptick in visibility in the US after the 2015 passage of marriage equality[2]. A transgender man (or trans man) is someone who was assigned female at birth but knows himself to be a man. A transgender woman (or trans woman) is someone who was assigned male at birth but knows herself to be a woman. Many transgender people, regardless of their birth gender, do not know themselves to have a gender that exists in the male-female binary. These non-binary genders have a variety of identifiers: non-binary, genderqueer, agender.

Estimates of the prevalence of transgender people domestically and globally are difficult to obtain. Transgender people both may be reluctant to disclose their gender identity to census respondent because of stigma, and the censuses themselves may not have an option to record the respondent as transgender. Using 2014 Behavioral Risk Factor Surveillance System (BRFSS, a long running domestic survey on health behaviors conducted by the CDC) data, the Williams Institute estimated that .6% of adult Americans identify as transgender for a total population of 1.4 million individuals[3]. While minors under the age of 18 are not included in the BRFSS dataset, it is worth noting that the 18-24 demographic had the highest percentage of transgender individuals at .7%, suggesting a higher prevalence of out transgender people in younger populations.

A transgender person's gender affirmation is a process referred to as "transition". Transition varies significantly from one individual to another. Some transgender people argue that the concept of transition itself is not valid: a transgender person was always the gender they know themselves to be regardless of whether or not that knowledge was socially affirmed[4]. Transition broadly falls into two categories. A social transition is when a transgender person begins to present as the gender they know themselves to be. Possible iterations of transition can include cutting hair or wearing makeup, using different pronouns, choosing clothes that matches their known gender, or updating legal documents to reflect their affirmed, rather than assigned gender. The primary institutional barriers with social transition are bureaucracies such as a state's Department of Licensing. While a transgender person needs documents that accurately reflect their gender for personal safety and access to employment, requirements vary greatly state to state. For example, West Virginia will only amend a birth certificate to accurately reflect a person's gender after proof is provided that they have undergone genital surgery to match their affirmed gender, or on a court order[5]. On the other hand, Washington State will

amend a birth certificate on submission of a letter from a physician or therapist supporting the individual's gender transition[6]. The second broad category of transition is known as medical transition. While there is no one set template of procedures for medical transition, these can include "top" surgery, either to reduce, remove or augment the breasts, facial feminization surgeries, taking hormones, utilizing puberty blockers to delay the onset or progression of puberty, and genital surgery or "bottom surgery".

Significant issues can arise from lack of access to medically supported transition. Individuals who wear a binder (a tight garment that holds down breast tissue to create a more typically masculine chest appearance) over long periods of time report may breathing difficulty, back pain and rib damage[7]. People with ovaries who are on testosterone are both less likely than cisgender women to receive gynecological care, and have increased ovarian cancer risk[8]. Transgender women report being ostracized from the traditional workforce because of lack of ability to "pass" as their affirmed gender, which can be ameliorated through hormones and facial feminization surgeries[9]. Lack of access to gender affirming procedures that increase a woman's ability to pass in the mainstream workforce can lead to participation in sex work[10], which contributes to the 19% of trans women around the globe who have HIV[11].

Transgender adolescents, and their access to medical transition, are a current topic of hot debate in current US policy spheres[12]. Some pundits point to news stories highlighting the coming out of very young transgender children such as Jazz Jennings[13] as evidence that the media and parental pressure unduly influence children's gender identity. The question of how old a child needs to be in order to transition either socially or medically is also hotly debated. The American Academy of Pediatric's (AAP) current position on transition for transgender children distinguishes between "persistently and consistently" gender non-conforming children, and "desisters". Persistent and consistent is an informal measure often used by pediatricians who work in gender to specify children who have persistently insisted on their self-identification as a gender other than the one they were assigned at birth over a significant period of time relative to the child's age, and who have been consistent in their identification. This is in contrast to desisting gender non-conforming children who vary their self identification over time from a different gender than their assigned gender, to their assigned gender, to identifying as non-gendered concepts like an imaginary creature[14]. AAP advocates for affirming persistent and consistent gender non-conforming children through an age-appropriate social transition developing in conjunction with the child's parents and benefits their immediate and long term mental health[1516]. This is an especially pressing concern, as transgender people have one of the highest lifetime suicide attempt rates of any population, at 40%[17,18]. Of those attempts, the vast majority (92%) occur before the age of 25[1]. While those numbers represent an astounding loss of life, there is a great deal of evidence pointing to the success of gender affirmation as a suicide intervention[19] .

Another barrier for healthcare access for transgender people is poverty. Transgender people are more likely than their cisgender peers to be under the federal poverty line with 26% of transgender people in poverty, compared to 15.6% of the general population[20]. Unlike many

other marginalized groups in the US, transgender people lack federal workplace protection, leaving them particularly vulnerable to employment discrimination[21]. This lack of workplace protections is compounded by lack of access to transition related healthcare; transgender people who struggle to "pass" as their affirmed gender are particularly easy to single out for discrimination.

Medical transition is handled very differently than social transition with regards to transgender children. While the AAP recommends social transition as soon as the parent will support the child, they are more measured in their support of medical transition for trans youth[22]. Current best practice is to offer pre-pubertal transgender children access to hormone blockers that delay the onset of pubertal symptoms until the age of 16, when children are allowed to choose whether they would like to begin non-reversible medical transition, such as starting hormone replacement therapy, or undergoing chest or genital surgeries[23].

In the best possible scenario, healthcare providers and family of transgender youth attempt to strike a balance between helping the child affirm their gender and maintaining developmentally appropriate boundaries. The process for supporting a possibly transgender child before puberty begins with the child meeting with a mental health professional to determine if they meet the diagnostic criteria for gender dysphoria or gender incongruence. If the child is diagnosed with GD/GI, social transition may be appropriate with the support of the family and a mental health professional. When the child reaches the Tanner 2 stage of pubertal development, pubertal blockers may be deemed to be appropriate. Gender affirming hormones may be offered around ages 13.5 to 16[24].

There is a great deal of evidence supporting allowing adolescents transitioning in a timeframe similar to their peers, both in terms of psychological well-being and developing normative peer relationships[25]. Allowing transgender adolescents to go through the puberty of their affirmed gender means that they will not have to engage in procedures that attempt to correct for the masculinizing or feminizing effects of exposure to their birth gender's hormones, avoiding procedures like tracheal shaves, electrolysis. Additionally, delaying the onset of puberty till the child and transition team feels comfortable going through the puberty of their affirmed gender means that the adolescent to physically develop in ways that are more in congruence with cisgender peers. This can look like young trans boy to experiencing the height benefits of taking testosterone, or having a trans girl not developing more feminine facial bone structure.

Transition and Insurance

Like managing any other medical condition in the US, the expenses of medical transition can be wildly burdensome. But beyond the simple weight of the load of the US healthcare system, transgender people seeking medical transition bear the weight of the "gatekeeper" model used by many insurance companies to regulate access to transition related care. Because insurance companies commonly ask for evidence that an individual is truly

transgender, an accounting of the costs for something as simple as clean needles for injecting hormones might need to include everything from a series of therapist visits establishing a mental health record, a series of primary care visits establishing good physical health, lab tests for any possible endocrine issues, as well as the standard copays, costs of clean needles and deductible. The costs for one of the most common procedures, a bilateral mastectomy, range from 9,000 dollars to have the surgery performed by one of the most skilled and well-regarded practitioners of the procedure in the US to around $2,7000 to have a surgeon in the Philippines perform the procedure[26].

A 2015 paper identified insurance exclusions as one of the primary barriers to care cited by transgender youth and caregivers[27]. Other barriers cited included:

> *(1) few accessible pediatric providers are trained in gender-affirming health care; (2) lack of consistently applied protocols; (3) inconsistent use of chosen name/pronoun; (4) uncoordinated care and gatekeeping; (5) limited/delayed access to pubertal blockers and cross-sex hormones; and (6) insurance exclusions [26].*

Trans youth in other papers also emphasized their preference for accessing not just transition related healthcare but all healthcare services with a provider who had high levels of competency in supporting transgender populations[28]. All literature of the topic of healthcare barriers for transgender youth emphasize the difficulty adolescents have in finding trans competent providers.

Just like how the majority of Americans pay for healthcare, most transgender people pay for their transition related medical expenses through health insurance. Obama era healthcare reforms greatly expanded access to Medicaid, and The Affordable Care Act (ACA) provides some universal protections for transgender people under marketplace plans, but does not guarantee access to gender affirming procedures. For example, sex-specific preventative services such as Pap smears have to be offered to transgender men, and transgender people can not be denied coverage because of their gender[29]. However, plans with “transgender exclusions”, meaning that they do not cover transgender health services such as hormones or gender affirming surgeries are allowed to participate in the market. There are also no federal laws regulating private insurance companies inclusion of transition relationed healthcare

The patchwork nature of ACA implementation and Medicaid expansion means that there is broad range of possible coverage or States have enacted a broad variety of mandates around transition-related care, ranging from ruling that both public and private health insurance plans must cover a variety of procedures, barring transgender exclusions in either Medicaid or private health insurance, to having no explicit policy banning exclusions in either public or private plans[30] .

Crowdfunding

Given both the lack of uniform coverage for gender affirming health care and the high rate of poverty among transgender people[31], crowdfunding is a logical alternative (or supplement) to traditional methods of paying for healthcare such as health savings accounts or health insurance to cover the out of pocket transition related cost. Crowdfunding is defined as an open call over the Internet for financial resources in the form of a monetary donation, sometimes in exchange for a future product, service, or reward[32]. A typical design for a crowdfunding campaign would be a single webpage raising set amount being raised for a specific cause or reason over a limited amount of time. The campaign is typically tagged with the geographic location of the recipient. The page has features usually including, but not limited to, a narrative describing why the funds are needed, a picture depicting the recipient or symbolizing the cause, a progress tracker showing the amount raised at that date, and a log of donations (either anonymous or with the donor's name).

Crowdfunding's rise has coincided with the rise of the eroding social safety net in the US and abroad. Berliner and Kenworthy note that crowdfunding is particularly popular in states with less access to public insurance[33]. However, their research suggests that campaign organizers who conform to specific narratives, or are able to "pitch" themselves sympathetically are more likely to be funded regardless of other variables [8]. Campaign organizers express pressure to hyper-empathizable in order to avoid blame and attract funds, at the cost of their dignity and privacy.[34] Preliminary research on reasons why transgender people might use crowdfunding to cover gender affirming healthcare costs, beyond lack of access to desired procedures through medical insurance or poverty, include flexibility (of amount to raise, time range to run campaign, how much to disclose or not), social support and affirmation, and enactment of political values such as collective responsibility for individual's wellness[35]. Gonzalez et al. emphasize that a crowdfunding campaign provides benefits that other out-of-pocket payments do not: engaging in highly vulnerable self disclosures can be experienced as empowering, being "out" about having a health condition can relieve shame, soliciting networks for material support can also yield a great deal of emotional support[36].

Methods

The primary question I began this investigation with was "*In randomly-selected samples, is there a higher number of transgender people conducting crowdfunding campaigns in states or countries where Medicaid does not mandate access to hormones for transgender people under 18?"* Some of the secondary questions this analysis addressed include regional trends in campaign goal levels, and whether people from regions with transgender healthcare insurance mandates are more likely to raise money for secondary procedures, like facial feminization, or for health care related expenses, including living expenses immediately post-surgery.

In this mixed methods ecological descriptive study I compared trends in states with an Medicaid expansion that included access to medical transition for transgender adolescent to

those who did not through the lens of crowdfunding practices to pay for a variety of transition related healthcare costs. I collected funding campaigns from three sources. Two sources were the crowdfunding sites YouCaring and GoFundMe. These platforms were selected because they are the most utilized crowdfunding sites in the US that allow funds to benefit an individual[37]. Sourcing campaigns from these two sites was expected to produce a roughly representative sample of relevant crowdfunding campaigns in the US.

I collected my case campaigns over a six week collection period from the set of campaigns that populated when the tag 'transgender' was searched on each site. The campaigns were then sorted by 'popular' to maximize the likelihood campaigns were active, legitimate, and current. Each day during the data collection period, I recorded the total number of campaigns I found under the 'transgender' tag.

I also conducted a sample of campaigns from the four most active US social media platforms with a majority of users under age 25 years. This was to capture part of the complexity of transition related health costs, and the difficulty of relying on an algorithm or tagging system to adequately capture the reason behind an individual's decision to raise money. For example, many solicitations I found were for non-binary people, a population that was not well represented under the 'transgender' tag on the two crowdfunding platforms I reviewed. These examples ranged from text posts on Facebook and Tumblr describing the beneficiary's need with a link to Paypal or Venmo, to recurring burlesque events organized monthly to benefit a different individual's transition expenses. I collected these cases from Facebook, Instagram, Twitter, and Tumblr[38].

I recorded the total number of campaigns I reviewed in order to reach the desired sample size. After recording total number of results, campaigns were evaluated in the order in which the site presented them until 50 campaigns meeting the inclusion criteria were found and recorded. I set a goal sample size of 50 cases from each site. Eight campaigns were deleted by their creators after the collection period ended, and four were included from social media for a total of 98 cases.

The following are the inclusion criteria that I used for all funding campaigns included in the sample:

- The beneficiary of the campaign was under age 26
- The beneficiary was self identified as non-cisgender
- The purpose of the campaign was to raise money for expenses broadly related to gender transition-related healthcare (ie, "Help a Trans Man Pay for Rent After Surgery" would be included while "Help a Trans Man Afford Rent" would not")
- The geographic location of the recipient was identifiable

To establish a baseline of what a state considered a necessary or reasonable, I used the list of procedures covered by Washington state's Health Care Authority (HCA) [39]. Other states, such as California and Oregon had very similar lists of covered procedures, and

Washington was selected for it's local relevance to the project. One of the procedures listed was "mammoplasty", which as a medical term, could apply to a variety of breast related surgeries ranging from mastectomy to augmentation. I called three of the five managed care organizations under Washington's Health Care Authority (Molina, United Healthcare, Amerigroup) to see what mammoplasty procedures they covered. While all covered mastectomies and related care, none covered augmentation or related care. Given this, I chose to treat campaigns seeking augmentations as outside the coverage mandate from the Washington HCA. The procedures covered were:

- Breast reconstruction
- Genital surgery
- Genital electrolysis as required as part of the genital surgery
- Hysterectomy
- Mammoplasty with or without chest reconstruction
- Metoidioplasty
- Orchiectomy
- Phalloplasty
- Placement of testicular prosthesis[40]

I listed all campaign recipients as the age that they were at the time the campaign started. If the campaign described the recipient as "turning x in a year" or "coming up on their x birthday, they were recorded as x-1. If the recipient was described as currently in high school but no age was given, they were recorded as <18. If the recipient was listed as currently in elementary school but no age was given, they were listed as <10. If the campaign was in non-US currency, the amount raised was converted to US dollars.

I coded each state or region as a binary variable of mandated or undmanated. The definition of those terms are:

1. Has legislation ensuring access to hormone replacement therapy for transgender people under age 18 in the state's Medicaid program, or the country's national health insurance, or (which I will refer to as mandated states)
2. Has no explicit/known legislation ensuring access to hormone replacement therapy for transgender people under age 18 in the state's Medicaid program, or the country's national health insurance (which I will refer to as unmandated states)

The reference for the states was the Movement Advancement Project's Medicaid policy map. The map is available as Figure 1 in the appendix.

I also collected information regarding whether the campaign recipient stated that they had private health insurance, and other ways they had attempted to pay for transition-related costs. If available, I collected demographic information. These variables were level of education,

race and whether the recipient had insurance

In the second stage of analysis, I qualitatively analyzed the text of randomly selected campaigns for deeper insight into the meaning of the campaign, and why they were initiated. Campaigns who included a description of the methods besides crowdfunding were recorded in initial data collection, and then compiled into a sub-sample. The reason campaigns with a description of alternate funding methods besides crowdfunding were selected for the subsample is that a description of alternate funding methods was an identifiable and concrete marker for having some level of description and explanation in the campaign narrative over and above a simple appeal for fund. There were 18 campaigns in the sub-sample. Using a random number generator, five campaigns were selected and then distributed to four reviewers. The samples were reviewed in a process of inductive analysis. Each reader developed a codebook through an iterative process of reviewing campaigns. Codebooks and samples from each reader were then reviewed against one another for consistency in themes.

Results

Quantitative Campaign Results

I found that there were more crowdfunding campaigns in states that did not have a mandate to cover hormones for transgender people less than 18 years of age under the state Medicaid program (referred to as 'mandated states') than in states with such a mandate (referred to as 'unmandated states'). In the sample of 98 cases, 59% (58) were from unmandated states, while 41% (40) were from mandated states.

The average goal amount for the campaigns in the sample was $7,365. Unmandated states had an average goal of $7,109, and mandated states had a goal of $7,735. Campaigns raised an average of 12.3% of their goal for a total of $910. Unmandated states raised an average of 10.5% at $732, and mandated states raised an average of 14.2% and $1,105.

Table 1. Campaign Characteristics By Mandated and Unmandated States

	Overall	**Mandated States**	**Unmandated States**
Percentage of campaigns from region and total number	100% (98)	41% (40)	59% (58)
Average age of campaign beneficiary	20.6	19.5	20.7
Average goal amount	$7,365	$7,735	$7,109

of campaign			
Average percentage of goal amount raised and amount raised in dollars	12.3% (910)	14.2% ($1,105)	10.5% (732)

According to the most recent review of state law, 32 states either explicitly ban transition related healthcare under Medicaid or have no explicit policy regarding transgender healthcare generally, while 18 states and the District of Columbia do mandate coverage [36]. Unmandated states comprise 53% of the total population of the US, and mandated states comprise 46%[36]. When population size was considered, unmandated states still had a prevalence of transgender health campaigns that is 6% higher than mandated states. Additionally, 52% of LGBT Americans live in a state with either no transgender health mandate or an explicit ban in Medicaid[41, 2642]. This is not adjusted for age.

Table 2: Campaign Goals by Inclusion in Washington Healthcare Authority (HCA) Compared by Mandated and Unmandated States

	Overall*	**Mandated States**	**Unmandated States**
One or more campaign goal not covered by WA HCA	50	16	34
All campaign goals covered by WA HCA	37	20	17

*Eleven campaigns in the sample were solely raising funds for unspecified surgeries

Campaigns from unmandated states were 2.2 times more likely than mandated states to have a campaign goal that was outside the set of covered procedures from Washington State's HCA. In contrast, campaigns from mandated states were about equally likely to ask for goals covered by HCA as not. Campaigns tended to raise money for multiple goals, such as hormones and facial feminizations. They asked for a complex range of transition assistance, including cryopreservation (freezing of the eggs), breast augmentation, binders or packers (gender affirming garments), costs of travel to and from surgery, electrolysis, and facial feminization surgery.

The dollar amounts raised by the campaign also differed for unmandated and mandated states. Campaigns in mandated states aimed to raise more on average than those in unmandated states. Campaigns in mandated states also raised more on average than those in unmandated states by almost $400.

Given that crowdfunding is, by its very nature, an alternative to traditional means of paying for healthcare, I wanted to examine the way campaigns in my sample discussed their relationship to more traditional means of paying for transition. Several campaigns discussed how they planned to pay for the procedures besides funds raised from crowdfunding.The most commonly cited method was personal savings (12 total campaigns) and 10 of those campaigns were from mandated states, followed by insurance (7 total campaigns). Men were slightly more likely to pay from personal savings than other genders. Users of personal savings were also at least one year older on average. They also tend to ask for slightly less money than the sample average ($7,004), but receive less than half as much as the average at $411.8. They also tend to be shared more than the campaign average at 189.3 social media shares, but have fewer donors at 12.3.

Gender

Table 3. Campaign Characteristics By Beneficiary Gender

	Overall	**Non-binary**	**Male**	**Female**
Percentage of campaigns from region and total number	100% (98)	2%	65.3%	31.7%
Average age of campaign beneficiary	20.6	20.0	21.2	19.7
Average goal amount of campaign	$7,365	$3,862	$5,848	$10,414
Average percentage of goal amount raised and amount raised in dollars	12.3% (910)	135%($5,000) -	17% ($1,000)	5.9% ($611)
Percentage of total shares on social media	100%	.57%	77.9%	21.5%

The demographics of the campaign beneficiaries skewed towards the late teens and very early twenties, and were twice as likely to be male as other genders. Overall, the average age of campaign beneficiaries was 20.6 years. In mandated states the average age was 19.5 and in unmandated states it was 20.7. Overall, the campaign beneficiaries were self described as 32.7% female, 65.2% male, and 2% non binary. When the number of times the campaigns were shared by supporters on social media platforms was considered, the male campaigns collected 77% of the total campaign shares. Campaigns benefitting males also collected 70% of the total donations. The female campaigns collected 21% of the shares, and 23% of the donations. The non-binary campaigns collected .6% of the shares and 6.6% of the donations.

The campaigns aimed to raise an average goal of $7,365. That amount varied a great deal by gender. The average goal amount for female campaign beneficiaries was $10,414, $5,848 for males and $3,862 for non binary. Mandated states averaged $1105 on a $7735 goal (14% of goal met), while unmandated states raised $732 of $7109 (10% of goal met). Broken out by gender, females had the lowest amount of goal amount for their campaigns reached at 5.9% ($611), followed by 17% for male beneficiaries ($1,000), and 135% for non-binary beneficiaries ($6,000). Men asked for less money than women by 5,470 dollars, and completed 11.1% more of their funding goal than women at 17% of goal reached as compared to 5.9%.

Campaigns in the sample lasted an average of 10.5 months. The average length of time for campaigns from mandated states was 7 months, and median month for a campaign to start in was July. Campaigns from unmandated states had an average length of 11.7 months, and the most common start months was February.

Regardless of location, gender, or payment systems only 18% of campaigns in the sample reached half or more of their goal funding amount.

Content and Thematic Results

A thematic analysis of campaign narratives revealed three key elements in the way campaigns were structured. Campaigns began with a description of the procedures being fundraised for and the logistical arrangements to receive the procedures ("*I am raising money for a double incision mastectomy surgery (also known as "top surgery*")[43]. The following element was a justification or explanation for why the procedures are desired. This was commonly linked with feelings of dysmorphia. ("*Everyone who knows me will know that I'm always wearing a hat; I don't leave the house without a hat and most of the time I can't look in the mirror without wearing my hat. I resent it constantly but at the moment there's nothing I can do about it ....This is something that governs how and when I'm able to leave my house and has a massive effect on my confidence and self-esteem. I don't want to be terrified of people seeing my face anymore[44].").* The final element was a plea, which addressed the reader with a request for help.

A subtheme within plea was apologizing and justification (*"Anything helps thank you so much. I hate asking i am also giving back with the options above)"*[42]

While demographic information such as race and educational attainment was collected, too few campaigns mentioned these to make any kind of systematic analysis based on these variables.

While it made sense to have a certain amount of campaigns asking for procedures outside of "standard" coverage lists like Washington state's, such as facial feminization or freezing eggs, campaign beneficiaries in mandated states also asked for many procedures that should in theory been covered. For example, out of the fourteen total campaigns in the sample from California eight asked for procedures that are explicitly covered under the state's Medicaid program. California also mandates that private insurance plans must cover transition related healthcare. Narratives from this sub-sample of campaigns did not discuss why they were seeking crowdsourced funds to cover the costs of transition and whether they used insurance, instead typically focusing on the beneficiaries personal story and worthiness of funds. A sample of this kind of narrative is this:

> ..*Drew has been out as transgender for several years and has finally turned 18 so he can start the medical side of his transition. Unfortunately, the medical side of this can be quite expensive so that's where you all can hopefully come in and help out! Drew is the sweetest, most generous person I know and I want to give back all the good he's done for me and everyone else. Anything helps, so if you can, please donate or share this campaign or both! I love Drew with my whole heart and he really deserves this. Thank you so much for your time, it is greatly appreciated*[45]*.*

A key theme in this narrative and others like it is the emphasis on the beneficiary as a worthy recipient. Describing him as "the sweetest, most generous person" emphasizes an emotional appeal to donate to benefit an individual. As Gonzalez's research into the psychosocial aspects of crowdfunding reveals, campaigns aren't merely a vehicle to raise money. Instead, they function as an appeal to both a known community (friends and family) and potentially to a larger, dispersed community of LGBT people who might spontaneously support a campaign based on the description of the recipient as worthy.

Discussion

The major finding of this study is that there is an association between whether a state had mandated coverage and the likelihood to have a campaign originating from that location. States without Medicaid covering transition related healthcare had more campaigns overall, even adjustments were made for the different populations of unmandated and mandated states. **This suggests that Medicaid expansion had a positive net effect on transgender**

adolescent's access to transition related healthcare. Given the effectiveness of transition as an intervention in transgender adolescents' mental and physical health, this finding is significant in terms of what it suggests about the importance of Medicaid expansion for the health of transgender adolescents.

Cultural differences may be partially responsible for the difference in mandated and unmandated state's total amounts raised. Unmandated states were primarily located in the Midwest and South, areas noted for their social conservatism. Transgender youth located in these areas may face more social stigma, and have smaller social networks overall. Previous research found that transgender youth tend to emphasize their online relationships as a source of resiliency, but these ties are typically weaker than in person social relationships[46]. Since the design of crowdfunding campaigns relies on the beneficiary's relationship network to fulfill the campaign goal, the potentially smaller and weaker networks of transgender youth in unmandated states would have a detrimental effect on their ability to fundraise to cover the cost of transition.

Similarly, there were significant disparities in who received shared of their campaign on social media. Given that shares of campaigns are the primary funding mechanism for campaign beneficiaries to reach their goal, the ability of a campaign beneficiary to get their campaign shared on social media platforms is a huge factor in their campaign's success. Women received 21% of the total social media shares for the sample, even though they represented 31% of the total campaigns, while men received nearly 78% of the total shares despite only having 65% of the total campaigns.

One of the biggest surprises of this study is was that there were many campaigns from mandated states. The existence of crowdfunding campaigns raising money for procedures that should, in theory, be accessible to all people in their state of origin points to an unknown confounder complicating the relationship between the existence of coverage for transition related healthcare in a state's Medicaid. An enormous body of literature has previously discussed healthcare access barriers from both a demographic lens (immigration status[47], mental and physical disability[48], and so on), and a policy lens (Medicaid's expansion did lead to a reduction in access barriers in adults[49]). However, I would like to propose another lens that is particularly vital for transgender youth accessing transition related healthcare: savvy. Beyond health literacy, savvy encompasses a beneficiary's ability to navigate through and massage a healthcare system to their benefit. Consider the California campaigns who were raising funds for procedures that were covered by their state's Medicaid. While there are variety of possible explanations for this finding, one of the simplest is that beneficiaries simply *did not know* either how to use insurance to pay for transition, or that using Medicaid to pay for transition was an option at all.

A secondary finding of this study is that gender is a major determinant of how much funding beneficiaries receive. Previous work in the field of crowdfunding research found that women tended to raise more money in crowdfunding campaigns and hypothesized that it was

due to their use of positive, vivid, and inclusive language in describing their appeal[50],[51]. However, this paper appears to be the first that shows that unlike their cisgender peers, transgender women are not as successful as transgender men at raising money through crowdfunding. The reasons for this distinction are not immediately clear. A review of the literature reveals that there is not a body of research on whether cisgender and transgender women use language differently, which would support the findings of previous research on gender differences in crowdfunding outcomes. Another possible reason is the previously discussed high level of social stigma that trans women face could extend to their ability to generate funds from their social networks. Similarly, trans women may have smaller, or less wealthy, social networks.

While the sample size is very small, an intriguing result from the study is that both of the non-binary campaign beneficiaries exceeded the average amount raised by an average of 123%. Further research into the relationship between a non-binary gender identity and ability to overcome healthcare access barriers is warranted.

The intangible benefits of generating social support and well wishes for transgender youth should not be underestimated, given their high rates of marginalization, poor mental health, and suicidality. However, as I review the gaps between the amount asked for and the amount raised, I am wary of recommending crowdfunding as anything beyond a tertiary method for raising funds to cover transition related costs. Given that the gap between the average amount asked for ($7,365) and raised ($910) was substantial, it is hard to make an argument that crowdfunding is a viable way for young transgender people to pay for desperately needed transition related care.

Strengths and Limitations

There are several key strengths to this study. One is that by combining an ecological study design with a qualitative analysis, I was able to both describe the phenomenon of transgender adolescent crowdfunding, and start to describe the motivations behind why the campaigns were initiated and why more traditional means of paying for transition related healthcare were not sufficient. The funding mechanisms that people use to pay for medical transition are complex and overlap. For example, six campaigns raised funds to cover the cost of co-pays for surgery. This indicates that the beneficiary has some degree of insurance, but has other barriers towards paying for the complete cost of transition. The design of this study allowed for some degree of this complexity to be considered and included in the final analysis.

While a larger sample would have generated more explanatory power and lent greater validity to any conclusions from the study, the limited time and resources of the study called for a smaller sample. However the sampling design of the study both drew on elements that maximized validity (selecting the two most commonly utilized crowdfunding sites to collect as broad a sample as possible, sorting by popular to weed out inactive or flawed campaigns) and

representativeness (adding every campaign that met a relatively broad inclusion criteria, working on sequential days to ensure a stable set of cases).

The inability to determine causality is another limitation of this study. Due to the ecological design of the study, the possibility of unknown variables that influence any given relationship between a state's inclusion of transgender healthcare in it's Medicaid mandate and the amount of crowdfunding transgender adolescents engage in can not be ruled out. The 2016 FCC Broadband Progress Report found that 10% of Americans lack access to broadband internet, which is the generally accepted standard for accessing the web[52]. Restrictions in internet access could be suppressing the amount of potential crowdfunding campaigns, particularly given the relationship between no internet access, poverty, and all the assorted complications of seeking healthcare in a rural setting. Additional potential confounding variables that could be worth exploring in future research include the role of political events (are people more likely to turn to crowdfunding when they feel uncertain about the future of Medicaid?).

Further research into this subject should evaluate what happens to campaign beneficiaries after the campaign. Given that so few campaigns reached their goals, a question of interest is what beneficiaries do next. Did the funds from the campaign help them speed up accessing medical transition when compared to peers who did not crowdfund? Additionally, exploring the impact of the dual social exposure/social support dynamic of crowdfunding over time could reveal insights into whether there are long term positive (increased social connection and community support) or negative (increased stigma, family rejection) from crowdfunding.

Conclusions

Transgender adolescents may need special outreach to educate them about their ability to use Medicaid to pay for transition, and guidance through overcoming access barriers to do so. Even with insurance, it is much more difficult for an adolescent to navigate through their insurance system than to create a crowdfunding campaign and hope that it will cover the costs of transition. Given the young age of the sample (all beneficiaries were under twenty-six), they have limited experience navigating the complex world of healthcare. The normal difficulties built into our current healthcare system are compounded by transgender youth's high rates of homelessness, parental rejection, and poor mental health. These factors possibly interact to create low levels of health literacy and "savvy" as a transgender adolescent attempts to navigate the system. **Healthcare navigators skilled in the needs of transitioning adolescents would be a worthy avenue for future policy development and funding.**

While there were was a set of common procedures (hormones and top surgery were the most commonly requested) that mostly fell in line with procedures that were covered by Washington state, there was enormous variance in what people asked for to support their transition. Campaign beneficiaries sought everything from help paying rent while recovering from surgery to help paying the filing fees for a legal name change. The individuality of any

given transgender adolescent's transition- related healthcare needs makes it unclear whether a general expansion of procedures covered in response to the needs of transgender adolescents needs to happen.

However, facial feminization surgery stood out as a highly desired procedure that was not covered by Washington State's Healthcare Authority. The surgery encompasses a set of procedures that bring a transgender woman's facial characteristics closer to the appearance of a cisgender woman, improving their ability to "pass". Initially, I saw this surgery as a function of vanity, not utility. But a transgender woman's ability to pass can be a matter of life and death, given the high rates of violence this community faces[53]. Passing can also improve a transgender woman's ability to gain work in the traditional workforce and avoid sex work[54], an issue that becomes particularly important when the high global and domestic rates of HIV in trans women who work in the sex trade is considered. Including facial feminization surgery in the set of covered procedures makes sense, especially in the context of covering the placement of testicular prosthesis, a purely cosmetic procedure that while important for it's role in combating dysphoria lacks the economic and safety benefits of facial feminization.

It is also important to note the limitations and possible negatives of emotional support through crowdfunding, especially for transgender adolescents who are already dealing with social stigma. While beneficiaries may receive a positive emotional boost from seeing their campaigns shared and interacted with, the reality that their campaign will not go far towards helping them access transition related care has the potential to be both discouraging, and discourage their ability to seek out and navigate through applying for and accessing health insurance. The long term effects of having a public campaign on the social well-being of adolescents should also be considered. Transgender crowdfunding campaigns typically include the full name and location of the beneficiary, and sometimes describe in explicit detail what kind of medical procedures the beneficiary will undergo. Since previous research on the impact of public crowdfunding on the well-being of transgender people has been on adults, further research into the long term impact of being publicly "out" in the way that crowdfunding demands, and having a record of their transition available.

Further research into the long term effect of crowdfunding for transgender adolescents should include development of a cost-benefit analysis. Factors to include in development of the model should include consideration of potential impact on employment, increased victimization and discrimination, draining of social capital, diversion of effort away from accessing Medicare,d and potential decreased family support.

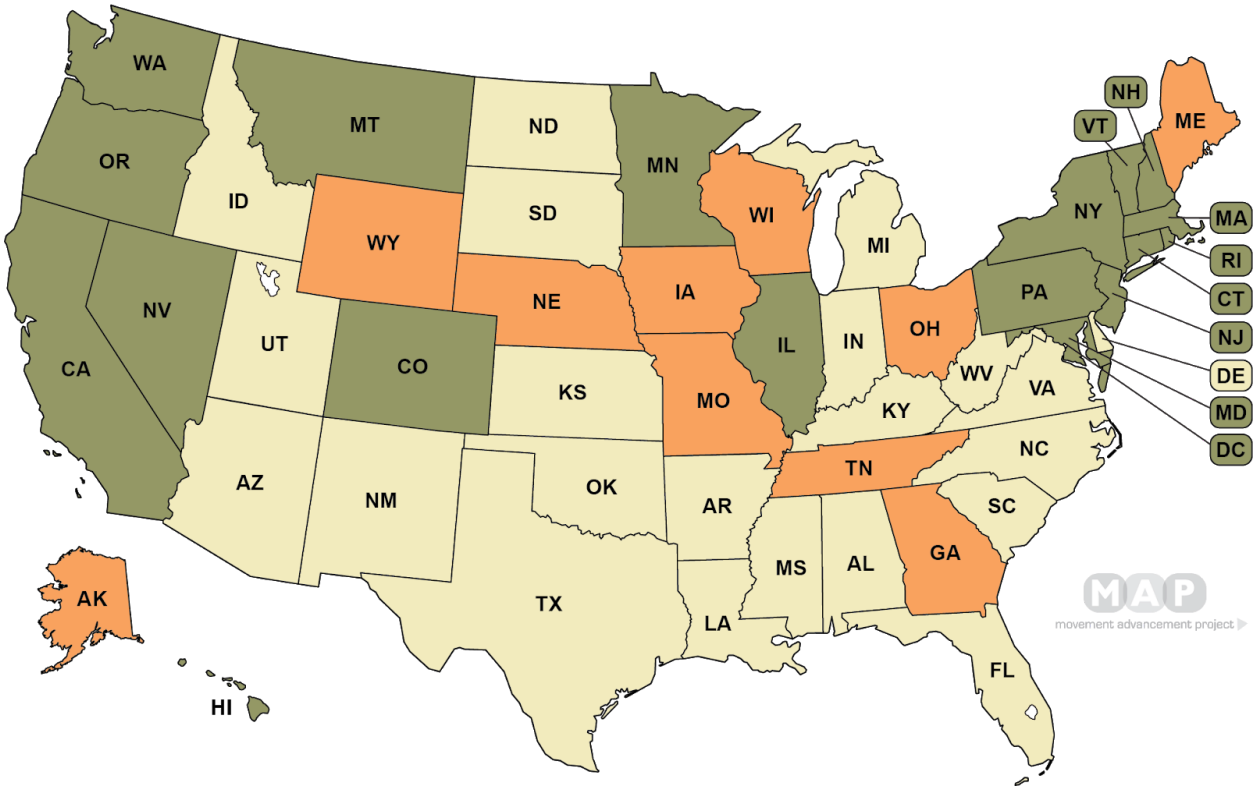
Healthcare providers and social workers discussing crowdfunding with their clients to cover the cost of transition should keep the following in mind:

- It is very unlikely that the campaign will cover even half of the cost. On average, transgender adolescents will typically raise only 12% of their goal.

- Emphasize that while they may experience surprising generosity from their community, particularly in terms of number of shares of the campaign on social media, it is highly unlikely that their campaign will “go viral” and receive donations from people they do not know.
- Crowdfunding campaigns reflect unmet needs. If the client is expressing a desire to crowdfund to pay for healthcare, it may be indicative of larger financial or psychosocial barriers worth discussion. Explore these topics with the client, along with any barriers to navigating Medicaid or private insurance, pursuing work, or borrowing money from family or friends to cover the cost of procedures before relying solely on crowdfunding.

Appendix

Figure 1



- Green- State Medicaid policy explicitly covers health care related to gender transition for transgender people*(18 states + D.C.)*
- Beige- State Medicaid has no explicit policy regarding transgender health coverage and care *(22 states)*
- Orange- State Medicaid policy explicitly excludes transgender health coverage and care *(10 states)*

*(*Movement Advancement Project | Healthcare Laws and Policies. (n.d.). RetrievedMay15, 2018, from http://www.lgbtmap.org/equality-maps/healthcare_laws_and_policies)

Endnotes

1. Feinberg, Leslie. *Transgender warriors: making history from Joan of Arc to Dennis Rodman*. Beacon Press, 1996.
2. Redden, Molly. “Transgender Rights Activists Look for Support after Marriage Equality Victory.” *The Guardian*, Guardian News and Media, 19 Jan. 2016, www.theguardian.com/world/2016/jan/19/transgender-rights-gender-expression-non-discrimination-act-new-york.
3. Flores, A. . *How Many Adults Identify as Transgender in The United States?* Williams Institute.https://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf
4. Cotten, Trystan T., ed. *Transgender migrations: The bodies, borders, and politics of transition*. Routledge, 2012.
5. Statute: W. Va. Code § 16-5-25 (2006).
6. https://www.lambdalegal.org/know-your-rights/article/trans-changing-birth-certificate-sex-designations
7. Peitzmeier, Sarah, et al. "Health impact of chest binding among transgender adults: a community-engaged, cross-sectional study." *Culture, health & sexuality* 19.1 (2017): 64-75.
8. 2008 Jul-Aug;53(4):331-7. Gynecologic care of the female-to-male transgender man . Dutton L, Koenig K, Fennie K. Publisher: American College of Nurse-Midwives ISSN: 1542-2011, OCLC: 44405042 Journal of midwifery & women's health (Online)
9. Sausa, Lydia A., JoAnne Keatley, and Don Operario. "Perceived risks and benefits of sex work among transgender women of color in San Francisco." *Archives of Sexual Behavior* 36.6 (2007): 768-777.
10. http://www.transequality.org/sites/default/files/Meaningful%20Work-Full%20Report_FINAL_3.pdf
11. http://www.unaids.org/en/resources/campaigns/2014/2014gapreport/gapreport
12. J Adolesc Health. 2016 Sep;59(3):254-261. doi: 10.1016/j.jadohealth.2016.03.017. Epub 2016 May 24.
13. Grinberg, Emanuella. "Why transgender teen Jazz Jennings is everywhere." *CNN Online* (2015).
14. Steensma TD, McGuire JK, Kreukels BP, Beekman AJ, Cohen-Kettenis PT. Factors associated with desistence and persistence of childhood gender dysphoria: a quantitative follow-up study. *J Am Acad Child Adolesc Psychiatry*. 2013;52(6):582–590pmid:23702447
15. Sherer, Ilana. "Social transition: Supporting our youngest transgender children." *Pediatrics* 137.3 (2016): e20154358.
16. Olson KR, Durwood L, DeMeules M, McLaughlin KA . Mental health of transgender children who are supported in their identities. *Pediatrics*. 2016;137(3):e20153223
17. James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.
18. Sally C. Curtin, M.A., and Margaret Warner, Ph.D., (2016), Suicide Rates for Females and Males by Race and Ethnicity: United States, 1999 and 2014
19. Clements-Nolle, Kristen, Rani Marx, and Mitchell Katz. "Attempted suicide among transgender persons: The influence of gender-based discrimination and victimization." *Journal of homosexuality* 51.3 (2006): 53-69
20. Quintana, Nico Sifra. "Poverty in the LGBT Community." *American Progress* (2009).
21. Crissman, Halley P., et al. "Transgender demographics: a household probability sample of US adults, 2014." *American journal of public health* 107.2 (2017): 213-215.
22. https://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/AAP-Statement-in-Support-of-Transgender-Children-Adolescent-and-Young-Adults.aspx
23. Olson, Johanna, Catherine Forbes, and Marvin Belzer. "Management of the transgender adolescent." *Archives of pediatrics & adolescent medicine* 165.2 (2011): 171-176.

24. Hembree, Wylie C., et al. "Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society clinical practice guideline." *The Journal of Clinical Endocrinology & Metabolism* 102.11 (2017): 3869-3903
25. Bockting, W. O., & Coleman, E. (1992). A comprehensive approach to the treatment of gender dysphoria. In W. O. Bockting & E. Coleman (Eds.), *Gender dysphoria: Interdisciplinary approaches in clinical management* (pp. 131–132). Binghamton, NY: Haworth Press.
26. http://www.topsurgery.net/costs/, Accessed 2/26/16
27. Gridley, Samantha J., et al. "Youth and caregiver perspectives on barriers to gender-affirming health care for transgender youth." *Journal of Adolescent Health* 59.3 (2016): 254-261
28. Hoffman, Neal D., Katherine Freeman, and Stephanie Swann. "Healthcare preferences of lesbian, gay, bisexual, transgender and questioning youth." *Journal of Adolescent Health* 45.3 (2009): 222-229.
29. https://www.healthcare.gov/transgender-health-care/
30. http://www.lgbtmap.org/equality-maps/healthcare_laws_and_policies
31. Quintana, Nico Sifra. "Poverty in the LGBT Community." *American Progress* (2009).
32. P. Belleflamme, T. Lambert, and A. Schwienbacher, "Crowdfunding: Tapping the Right Crowd," in International Conference of the French Finance Association (AFFI), May 11-13, 2011, 2011
33. Berliner, Lauren S., and Nora J. Kenworthy. "Producing a worthy illness: Personal crowdfunding amidst financial crisis." *Social Science & Medicine* (2017)
34. Gonzales, Amy, and Nicole Fritz. "Prioritizing Flexibility and Intangibles: Medical Crowdfunding for Stigmatized Individuals." *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2017.
35. Paulus, Trena M., and Katherine R. Roberts. "Crowdfunding a "Real-life Superhero": The construction of worthy bodies in medical campaign narratives." *Discourse, Context & Media*(2017).
36. Gonzales, Amy L., et al. ""Better everyone should know our business than we lose our house": Costs and benefits of medical crowdfunding for support, privacy, and identity." *new media & society* (2016): 1461444816667723.
37. Hemer, Joachim. *A snapshot on crowdfunding*. No. R2/2011. Working papers firms and region, 2011.
38. The first three were selected as the three top most active US platform, and the fourth was selected as having a high percentage of users under age 25 (http://www.pewinternet.org/2015/08/19/mobile-messaging-and-social-media-2015/2015-08-19_social-media-update_05/)
39. https://www.hca.wa.gov/free-or-low-cost-health-care/apple-health-medicaid-coverage/transgender-health-program
40. https://www.hca.wa.gov/free-or-low-cost-health-care/apple-health-medicaid-coverage/transgender-health-program
41. United States Census Bureau. "Population Overview." census.gov. 11 Oct. 2010. Web. 15. May. 2018. https://www.census.gov/programs-surveys/decennial-census/data/datasets.2010.html
42. Movement Advancement Project | Healthcare Laws and Policies. (n.d.). Retrieved May 15, 2018, from http://www.lgbtmap.org/equality-maps/healthcare_laws_and_policies
43. https://www.gofundme.com/kaihunter87
44. https://www.youcaring.com/jamilaeve-788658
45. https://www.youcaring.com/drewanderson-872735
46. Singh, Anneliese A. "Transgender youth of color and resilience: Negotiating oppression and finding support." *Sex Roles* 68.11-12 (2013): 690-702.
47. Flores, Glenn, et al. "Access barriers to health care for Latino children." *Archives of Pediatrics & Adolescent Medicine* 152.11 (1998): 1119-1125.
48. Neri, Melinda T., and Thilo Kroll. "Understanding the consequences of access barriers to health care: experiences of adults with disabilities." *Disability and rehabilitation* 25.2 (2003): 85-96.
49. Sommers, Benjamin D., Katherine Baicker, and Arnold M. Epstein. "Mortality and access to care among adults after state Medicaid expansions." *New England Journal of Medicine* 367.11 (2012): 1025-1034.

50. Gorbatai, Andreea, and Laura Nelson. "The Narrative Advantage: Gender and the Language of Crowdfunding." *Haas School of Business UC Berkeley. Research Papers*(2015).
51. Barasinska, Nataliya, and Dorothea Schäfer. "Is Crowdfunding Different? Evidence on the Relation between Gender and Funding Success from a German Peer-to-Peer Lending Platform." *German Economic Review* 15.4 (2014): 436-452.
52. "2016 Broadband Progress Report." *Federal Communications Commission*, 29 Jan. 2016, www.fcc.gov/reports-research/reports/broadband-progress-reports/2016-broadband-progress-report
53. Dinno, Alexis. "Homicide rates of transgender individuals in the United States: 2010–2014." *American journal of public health* 107.9 (2017): 1441-1447.
54. Lenning, Emily, and Carrie L. Buist. "Social, psychological and economic challenges faced by transgender individuals and their significant others: Gaining insight through personal narratives." *Culture, health & sexuality* 15.1 (2013): 44-57.