



ARIZONA'S REFUGEES WITH DISABILITIES

2018

Status Report

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Refugees with Disabilities in Arizona

An overview

While the humanitarian crisis rages on throughout the world and in war-torn places like Syria, tens of millions of people are becoming displaced, creating millions of refugees around the world. A very small percentage of these refugees can resettle in the United States. In 2016, Arizona resettled over 5,000 refugees, including 820 refugees from Syria (Arizona Refugee Resettlement Program [RRP], 2018). In fact, Arizona resettled more refugees from Syria in 2016 than from nearly any other country, second only to the Democratic Republic of the Congo (RRP, 2018).

Ref·u·gee (n.) / someone who has been forced to flee his or her country because of persecution, war, or violence (*UNHCR*).

As the global community reacts to the refugee crisis, it must also address the most vulnerable among them – refugees with disabilities. Refugees with disabilities are among the most susceptible groups to exploitation (United Nations High Commissioner for Refugees [UNHCR], 2013), and could experience disability at higher rates due to the effects of war or limited access to care. In Syria, for example, epilepsy (14%) and developmental disorders (11%) are the most common diagnoses among children receiving mental health services (Hijazi & Weissbecker, 2017). Yet refugees with disabilities remain underserved and underrepresented, even after they are resettled.


The Arizona Developmental Disabilities Planning Council (ADDPC) is a federally funded grant-making institution whose mission is to develop and support capacity building and systemic change to increase inclusion and involvement of people with developmental disabilities in their communities through the promotion of self-determination, independence and dignity in all aspects of life. www.addpc.az.gov

Although there is no international reporting agency on disability, and data on disability prevalence is seriously lacking in places like Africa and parts of the Middle East, the World Health Organization (2018) projects the number of people with disabilities to be around 15 percent of the world's population. This translates to potentially millions of refugees and displaced persons with a disability worldwide and potentially hundreds or even thousands of refugees with disabilities currently living in Arizona.

As for Arizona's general population, it has been reported that 12.6 percent of all residents have some form of disability (US Census Bureau, 2016). Such a significant proportion of Arizona residents with disabilities demands the existence of organizations dedicated to delivering services and providing resources to the disability community, including refugees with disabilities. The Division of Developmental Disabilities (DDD) and Vocational Rehabilitation (VR) are Arizona's dedicated state agencies to serving the disability community. But apart from them are literally dozens of organizations and nonprofits around the state that provide services and resources for persons with disabilities.

Unfortunately, these resources are not widely known and thus underutilized by refugee resettlement agencies (RAs) in Arizona. In addition, some disability organizations might not have the tools necessary to address the needs of refugees with disabilities in a culturally or linguistically competent way. So, when refugees with disabilities resettle in Arizona, how can disability organizations and RAs bridge the awareness gap and better coordinate their efforts to connect this population to services and resources they need or could benefit from? The purpose of this report is to highlight the gaps in areas that currently exist in serving refugees and to spark a dialogue that will better coordinate their access to services and resources, so they are included in community life.



 A note on the refugee intake process: After the refugee is referred to the U.S. for resettlement by UNHCR, biographical data is collected on the refugee as part of the security screening process and to prepare for an in-person interview. The biodata includes age, ethnicity, religion, gender, language, and education, but does not include disability. When refugees are approved by the Department of Health and Human Services, they undergo a domestic medical screening that looks for diseases of concern to public health, like tuberculosis. Disability diagnoses are not generally given at this stage. There is no tracking or reporting mechanisms in place to document disability, so figures reporting disability among the refugee population are merely estimates.

What We Learned

To gather as much information about the population of refugees with disabilities in Arizona, researchers from the Arizona Developmental Disabilities Planning Council (ADDPC) contacted the Arizona RRP and all seven RAs in Maricopa and Pima counties that contract with them.¹ Among all RAs, a total of 19 individuals participated in our interviews.

Our central focus was to learn about barriers or challenges refugees with disabilities and RAs experience when trying to access services. We documented RAs' responses and categorized them under common themes, which are represented in Figure 1. The categories include **system navigation, language, cultural barriers, and employment**. Participants also provided several recommendations for better serving refugees with disabilities, which we incorporated into this report.

¹ Refugee resettlement agencies include the International Rescue Committee (Maricopa), Catholic Charities Community Services (Maricopa), Lutheran Social Services of the Southwest, (Maricopa), Arizona Immigrant and Refugee Services, International Rescue Committee (Pima), Lutheran Social Services of the Southwest (Pima), and Catholic Community Services of Southern Arizona (Pima).

System Navigation

We marked 47 separate instances in which participants commented on various issues over navigating the system. The most prevalent of which was the lack of awareness RAs had on resources available to people with disabilities, outside of DDD and VR. Moreover, some RAs said they had issues locating and identifying resources for refugees experiencing serious mental illness, behavioral health issues, and complex medical needs.

There are several reasons why this is the case. The most prevalent reason is that resource allocation among these service organizations are ever changing, making institutional knowledge difficult to retain. Participants noted they do not receive many disability-related trainings to become sufficiently aware of the broad range of disability service organizations around the state.

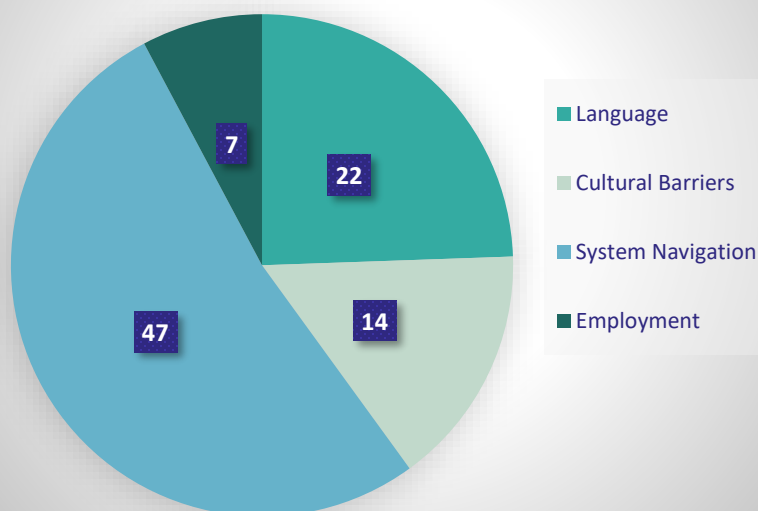
Language: language barriers, lack of trained interpreters, providers that don't provide interpreters, or the lack of awareness on Title VI.

Cultural Barriers: the stigma of disability, lack of advocacy, or detection of disability.

System Navigation: the lack of knowledge of resources; fragmented/complex system; cultural competency issues; communication structure issues, time consuming processes; and transportation.

Employment: stigma, language barrier, and the level of need an individual has for employment.

Figure 1. Number of Participant Comments



For instance, some RAs had never heard of programs like the Arizona Early Intervention Program (AzEIP), which supports families and their infants or toddlers with developmental delays or disabilities, or Raising Special Kids (RSK), another program providing programs and services to families of children with special needs, until age 26. Participants stated most information they receive about available

services for refugees come from DES but can be too generalized and not necessarily specific to disabilities.

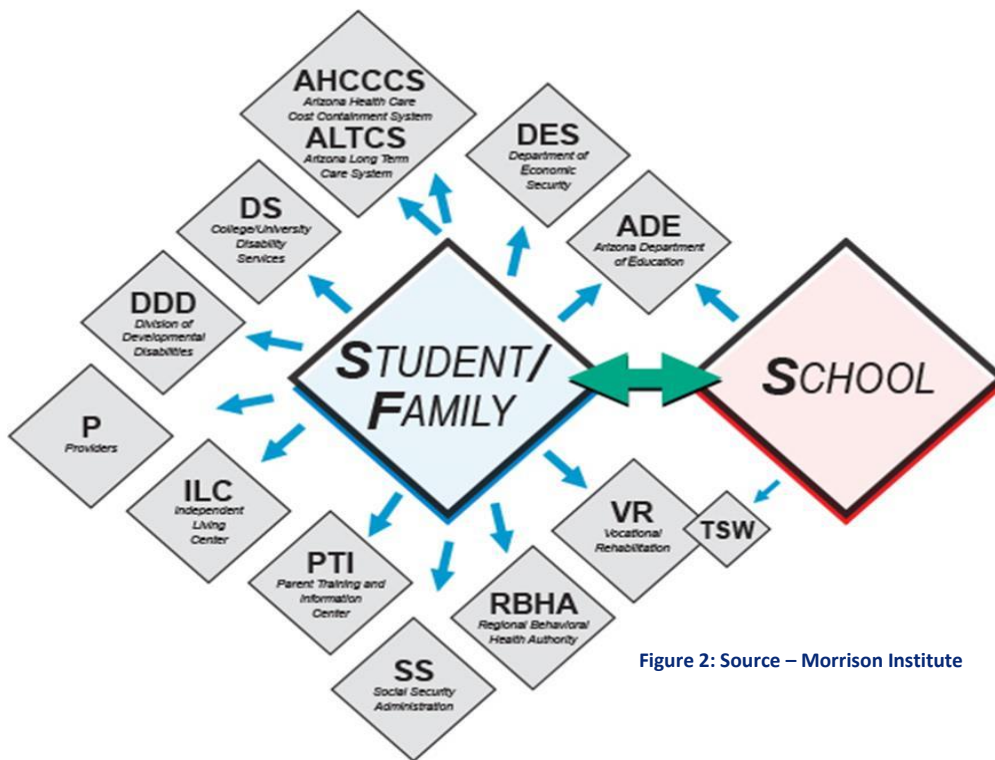


Figure 2: Source – Morrison Institute

Some participants emphasized the role schools play in identifying potential learning or developmental delays with refugee students.

However, this process can be quite lengthy because they first must determine if the student is just unfamiliar with being in a classroom or if in fact a disability exists. Even if a disability is identified, most RAs mentioned how time consuming it can be to connect refugees with disabilities to services from the state’s VR and DDD, especially for newly arrived refugee children. For a family to begin the daunting process of receiving services, they must follow multiple steps and engage multiple agencies, as Figure 2 illustrates. Additionally, one RA noted to fill out a DDD application to receive services, they first had to collect information from the Primary Care Physician and the school. The RA said DDD will not accept an application until the school performs an IQ test, which usually takes place after the child has been in school for almost a year. Simply put, in such an instance, a child in need of services would simply go without at a time when their need is most dire.

We also found RAs have issues with medical personnel, service providers, or other entities not being culturally competent in serving refugees. One RA described how difficult it was to enroll one of their clients in VR. Their client was blind but was not born blind. VR had trouble understanding why the client had not gained working skills before he or she became blind, perhaps not understanding economic structures and expectations are often different across cultures.

“It’s 90 percent language barrier and 10 percent strategies of communication that is at issue.”

- RA participant

Clearly, refugees come from various countries and cultures that may have different expectations than we do about care, communication, or social interactions. According to many participants, the cultural competence of an individual or organization can directly impact the quality of service and care a refugee receives.

As an example, one participant cited strategies for communication as another layer to cultural competence. “Wrapped up in interpretation are the strategies for communication that are culturally competent. So, it’s 90 percent language barrier and 10 percent strategies of communication that is at issue.” In fact, one of the RAs recalled a time where they invited a disability organization to present to refugee parents on guardianships. But the language used was too technical and it was overwhelming and confusing for the parents and even the RA staff. They were not invited to speak again.

Language

There were 22 comments on language-related issues. Not surprisingly, the language barrier accounts for most of them and is largely implicit within most of the issues outlined in this report. All RAs suggested language barriers are one of the biggest obstacles to connecting refugees to services. Language barriers manifest themselves in nearly all situations. For example, some RAs said their clients are occasionally

turned away from DDD because no one at the agency spoke their language. Since some refugees do not speak English, RAs reported doctors, insurance companies, and medical personnel end up speaking to the case manager about their clients, even though the case manager might not know the client's/refugee's entire medical history.

Nearly all RAs said there was a significant deficit of professionally-trained interpreters across the system and are hard to locate. Often, interpreters are neighbors of the refugees and are usually former refugee themselves, but they are not always linguistically competent, particularly in terminology used in areas of healthcare. However, most RAs utilize telephone interpreting services when there are not enough interpreters in the office or to protect a refugee's anonymity during a sensitive medical or psychology session. One of the most commonly cited interpreting services was LanguageLine, a service which connects a "Limited English Proficient" speaker with a professional language interpreter over the telephone.

Despite its convenience, interpreting over the telephone is not always sound since interpreting can also include reading body language and other physical cues. One participant suggested refugees connect with their interpreters over Skype or on a tablet or iPad, so they can see each other's faces. LanguageLine has recently added video remote interpreting to their services, but unlike LanguageLine, Skype can be downloaded and used for free.

Many participants also expressed concern over interacting with providers that receive federal dollars but are unfamiliar with Title VI of the Civil Rights Act of 1964, which is defined as such:

No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

The U.S. Department of Health and Human Services (2013) adds that persons with “limited English proficiency must be afforded a meaningful opportunity to participate in programs that receive Federal funds.”

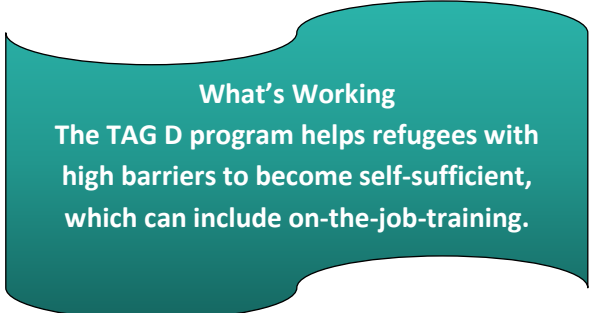
One participant surmised that up to 60 percent of service providers were unaware of their obligations to provide language interpreters under Title VI. Furthermore, RAs made clear providers that accept AHCCCS must pay for interpreters, but one participant remarked nine out of 10 providers that take AHCCCS do not know that.

Cultural Barriers

We recorded 14 comments regarding various cultural barriers, with the clear majority of them involving the stigma and shame disability has in many cultures around the world. For example, one participant recalled an incident emblematic of what many RAs said they experienced with their clients. They described an instance in which a refugee and his interpreter sat down with a DDD representative. The DDD representative asked the refugee if he was struggling with mental health issues, to which the refugee replied he had not, even though he had. So, although there was a language interpreter present, there was some other cultural barrier preventing the refugee from answering honestly or understanding the process.

Additionally, some refugees have been hesitant about disclosing mental or behavioral health issues for fear of being put into a government database that could be used against them. However unfounded that fear may seem to some, it is understandable given the corruption and persecution the refugee might have experienced from their government in their home country.

Participants also commented that some cultures might look upon disability like epilepsy with superstition, believing, in some cases, the person to be possessed by evil spirits. One participant said this was especially problematic if the parent or caregiver refuses to administer anti-convulsants or other necessary medications.



What's Working
The TAG D program helps refugees with high barriers to become self-sufficient, which can include on-the-job-training.

One participant said some refugee parents of vulnerable children have had issues with the Department of Children Services (DCS) because of perceived neglect if the child is not enrolled in school or does not receive adequate medical attention. However, it is often the case the parent was unaware of state and federal laws mandating school enrollment or even how to access medical care. Further, it can take a long time to convince some parents their children with disabilities need to be enrolled in school when their home country may have forbade them from doing so. All these stigma-related issues have proved challenging for RAs because it can interfere with a refugee's willingness to disclose disability in any form, prolonging or even preventing essential care from being delivered to refugees in need.

Employment

Employment-related issues figured less prominently in this report. This is likely due, in part, to RAs focusing their efforts to finding employment for the most job-ready or self-sufficient refugees first. Moreover, participants noted the lesser need for some refugees with disabilities to be employed as most are eligible for some public benefit, like Social Security Disability. One participant stated even some refugees with disabilities wanting to work have had a hard time holding down a job because it proved problematic for employers who were already dealing with a language barrier. However, in limited cases, RAs said they have had success with getting refugees with disabilities employed. It is usually through programs, like the Targeted Assistance Discretionary Program (TAG D), that provide extra services for vulnerable populations within the refugee community. TAG D helps refugees facing additional barriers to achieving economic self-sufficiency through employment, which includes on-the-job-training.

Recommendations

RAs shared a few ideas that may improve system access for refugees with disabilities. They remarked that efforts should be focused on improved interpretation services, access to information and resources for people with disabilities, and better coordination between agencies. In the conversations, there was also much discussion regarding schools. The following are some of the key recommendations mentioned:

Interpretation

- Agencies receiving federal dollars should include interpretive services in their budget.
- Interpreters should use Skype or IPAD with refugee clients.
- Interpreters should accompany refugees to medical appointments.
- AHCCCS should cover interpreters at their full rate and not just partially, in some cases.

Information and Resources

- DES meetings should offer presentations on services specific to disabilities.
- Passionate professionals need to be hired that are driven to help connect refugees with disabilities to resources.
- More resources should be equipped to serve refugees.

Better Coordination

- There needs to be better communication between disability and refugee communities.
- Refugee organizations and communities can benefit from increased training on programs that promote disability employment.
- Some organizations should be more flexible on who they serve, i.e. serving individuals without AHCCCS.
- Organizations should select a point person who is familiar with refugees and extreme medical cases.

School Support

- DDD, the Social Security Administration (SSA), or another agency should administer IQ tests, so schools are not overwhelmed.
- Responsiveness between the child with a disability and the school psychologist needs to be improved.

Disability Organization Input

Based on feedback we received from in-person and telephone interviews with RAs in Arizona, the ADDPC created a survey specifically for disability agencies and organizations and disseminated it to disability organizations located in Tucson and Phoenix – locations where refugees are resettled. The survey findings from the 13 organizations, along with data from the RA interviews, will highlight areas to improve coordination efforts between RAs and disability organizations/agencies so that refugees with disabilities are more effectively served.

Results confirm coordination efforts are very low between RAs and disability organizations/agencies. However, we find most survey respondents are interested in expanding their capacity to serve refugees, which includes receiving training on better serving refugees as well as delivering training on disabilities and disability-related issues.

The survey findings, together with the RA interviews, indicate a path toward raising awareness and improving communication between RAs and disability organizations/agencies. Still, one challenge we hope to resolve over the course of this report and further discussions, is how to support organizations that want to better serve refugees. As one respondent put it:

Our staff size is extremely small and often struggles to complete its current slate of tasks. At this time, while we would like to serve refugees to a greater degree and are interested in receiving training for this purpose, our ability will be limited (Survey respondent, 2018).

Specifically, the survey asks questions that help us learn how often disability organizations/agencies serve refugees, their process for serving them, and about respondents' interactions with RAs. Other questions relate to cultural and linguistic competency. Finally, the survey asks about trainings, including whether disability organizations/agencies ever receive trainings from RAs on refugees or give trainings to RAs on disabilities.

Findings

1. How disability organizations/agencies serve refugees and their interactions with RAs

The survey revealed slightly less than half of the participating disability organizations and agencies had served refugees. Of the 13 respondents, five said they had served refugees; seven said they had not; and one respondent did not answer. Moreover, only three respondents said their organization/agency had a process in place to serve refugees while 10 respondents said they did not have one. Nevertheless, most respondents expressed interest in expanding their capacity to serve refugees.

Most respondents do not engage in coordination efforts with RAs. Four respondents acknowledged working with RAs while eight participants had not. Respondents who have worked with RAs cited working with the International Rescue Committee (IRC), Lutheran Social Services, Catholic Social Services, and the Department of Economic Security Refugee Resettlement Program.

Of the five respondents who said they had served refugees, only one knew how many refugees contacted their respective agency/organization on average each year. This respondent stated that about six refugees contacted their agency/organization each year, which accounted for less than one percent of their clientele.

Respondents credit certain methods with their success in serving refugees. Respondents noted outreach efforts, partnerships with ethnic social agencies, quality customer service, and going into the community to meet with clients contributed to their successful outcomes. However, one respondent revealed some services, like translation services, were cost prohibitive given the small population size of refugees requesting their services.

2. Cultural and Linguistic Competency

The survey asked how disability organizations/agencies ensure their services are provided in a culturally competent way. For questions regarding cultural competence, respondents were given a definition from the Administration on Developmental Disabilities (2000), which defines cultural competence as:

Services, supports or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program.

We found most respondents' answers could be put into three basic categories: training; partnering with community members; and learning about diversity and different cultures. Some respondents stated their staff receives training on cultural competency and sensitivity. Others detailed that if necessary they would seek out partners from the community to help serve clients from different ethnic and cultural backgrounds. Finally, some respondents explained that learning about different cultures and emphasizing acceptance of diversity, which includes having a diverse staff, was key to delivering services in a culturally competent way.

The survey asked what the disability organization/agency would do if someone who spoke a language other than English or Spanish sought out its services/resources. Of the nine respondents who answered, five acknowledged that they would need to call LanguageLine or a similar telephonic translation service. The other respondents said they would seek out people who could translate or would refer clients to a community partner who could help.

Respondents were asked how confident they were that their staff would follow the same process if a consumer did not speak English or Spanish. Respondents said they were confident to very confident their staff would follow the same process.

Finally, seven respondents said they knew their legal requirements for providing services and resources to linguistically diverse populations. One respondent said they did not know and five did not answer.

3. Trainings

Only two respondents said they had received training on how to serve the refugee or other linguistically diverse populations. One respondent said the training involved presentations from refugee resettlement agencies that covered cultural awareness and Language Line. The other respondent wrote they had participated in a cross training with refugee resettlement agencies, stating, “They informed us about the history of the resettlement program, barriers refugees face, and provided tips on working with the population.”

However, most expressed the need for training. Eight respondents said they were interested in receiving training on how to serve the refugee or other linguistically-diverse populations.

We are willing to be better prepared in helping any refugees or linguistically diverse population

trainings to refugee families and/or refugee resettlement agencies, and seven said that had not. Six respondents expressed interest in providing disability-related trainings to refugee families or resettlement agencies, not including the two respondents who already had.

On the other hand, very few are providing training to RAs. Only two respondents stated they provided disability-related

The survey asked the respondents who said they provided disability-related trainings, how the trainings were delivered in a culturally competent way. This question received a single response. The respondent did not know how the trainings were delivered in a culturally competent way but noted there was an opportunity to improve their understanding of cultural competence. “We are willing to be better prepared in helping any refugees or linguistically diverse population,” wrote one

respondent. This reflects a common sentiment among respondents. In areas where they lack awareness or experience, they expressed a willingness to learn and grow.

Conclusion

Many refugees with disabilities and their families already feel overwhelmed after they have resettled in Arizona. Not only are they encountering an American culture that is completely different than their own, but the expectations of people with disabilities in the U.S. are vastly different too. U.S. laws protect people with disabilities from discrimination in education, employment, access to public accommodations, healthcare, housing, transportation, among many other areas. With these civil rights come an abundance of expectations to go to school, get a job, and live independently to the extent possible. Services delivered through a complex web of both state agencies and non-governmental organizations help individuals to do that.

For refugee families, these services can positively impact the lives of their loved one with a disability, as well as the entire family unit in a significant way. The provision of disability services, such as early intervention, assistive devices and technology, home care, paratransit, supported employment and employment training, adaptive recreation, peer support, and leadership training are just a few of the many programs out there. However, this report finds that access to these services are inconsistent, and in some cases non-existent.

Both RAs and disability organizations exist to improve the lives of the individuals they serve, but they are systems that have large caseloads with significant needs, staff turnover, and limited resources. In turn, RAs struggle to navigate a system where resources for disabilities are complex, ever-changing, and may not always be linguistically or culturally competent. Some disability services do not have interpreters available, but find they are financially limited in their capacity to hire them; while others have interpreters but do not know how to present information in a way the refugee family or the RA can understand.

The problem will not go away on its own. True, the number of refugees from certain countries accepted to enter the United States has fallen significantly in recent months

due to President Trump's travel determinations, but, the U.S. still accepts refugees. And refugees will always have a higher rate of disability compared to the general population due to several factors, such as trauma, violence, and inadequate healthcare.

This report finds that both RAs and disability service organizations are interested in improving communication and strengthening coordination efforts to more effectively serve refugees with disabilities. Training between agencies, periodic sharing of resources, assigning a contact, and understanding how to access interpreters were all suggested strategies to improve access. The system is already so complex among U.S. citizens – increased collaboration between these agencies can only serve to strengthen the outcomes for the entire family.

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