

Partners in Policymaking Feasibility Study

Feasibility Assessment, Partners in Policymaking in Spanish and Chinese

Final Report

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February, 2019

This project was funded by NYS Developmental Disabilities Planning Council Grant # T02433

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Partners in Policymaking Feasibility Study

Purpose of Feasibility Study

The New York State Developmental Disabilities Planning Council (NYS DDPC) committed one year of funding to the K. Lisa Yang and Hock E. Tan Institute on Employment and Disability (YTI), in the ILR School at Cornell University to conduct a feasibility study on creating a culturally competent and linguistically accessible Partners in Policymaking (PIP) course for Spanish and Chinese speakers in New York State. A culturally and linguistically competent program considers the needs of individuals with limited English proficiency (LEP) and those with disabilities that come from diverse backgrounds with different communication needs. Additionally, a program is culturally and linguistically competent when its content provides value and significance to people of all cultures, backgrounds, and languages.

Because New York's Partners program is only available in English, the purpose of the study is to assess the degree to which the existing program approach and curricula reflect a culturally inclusive approach to program design and delivery and the feasibility for translating the program into other languages. The YTI staff and faculty worked in collaboration with the DDPC to obtain input from external stakeholders, conducted an analysis of the extent to which the current Partners program model and curriculum have relevance, merit and 'transferability' within and across multi-cultural groups and especially those for whom English is not the primary language.

The feasibility study was initiated in January 2018 and ended in December 2018, and included a multi-phase approach to strengthen the cultural and linguistic competency (CLC) of the NYS Partners program. The current report provides a summary of each phase of the study.

- Review of literature on CLC -- The researchers conducted a review of the literature and reviewed demographics of the NYS population. The literature also provides foundational knowledge of the cultural and linguistic concerns of Chinese Mandarin and Spanish-speaking individuals with intellectual and developmental disabilities.
- Self-Assessment on the CLC of Partners Course -- We conducted a self-assessment by reviewing the evolution of the Partners program and assessed challenges to embedding principles of cultural and linguistic competence in the current Partners in Policymaking model. The self-assessment also included feedback from two groups of advisors: Spanish speakers and Chinese speakers. The advisors provided initial feedback on the current program using a checklist designed explicitly for our purpose. The feedback supported the development of a focus group protocol.
- Focus Groups with Chinese and Spanish-speaking community members -- We interviewed several focus groups to gain a deeper understanding of the experience of Chinese and Latino individuals with disabilities and their family members. Participants were provided an overview of the Partners course format and content and asked to respond to specific questions related to their real and perceived need and interest.

- Language Access Plan and recommendations for improving Partner’s CLC -- We developed a Language Access Plan¹ for the program as well as a list of recommendations to support the future effort in enhancing the cultural and linguistic competence of the Partners program.

Overview of the Partners Program

The NYS DDPC funds the YTI, to design and implement the New York State Partners in Policymaking (Partners) disability advocacy and leadership development program. New York’s program model is a derivative of the national Partners program model originated in 1987 by the Minnesota Governor's Council on Developmental Disabilities during the height of the rally for the Americans with Disability Act. The handbook indicates the Partners in Policymaking was developed to train participants in best practices over a wide range of issues and to teach the skills necessary to change systems. Up until this, families and individuals with disabilities did not have a platform through which to obtain information and skills necessary to influence issues that were directly impacting their lives. At this important time in disability history, members of the Minnesota Council recognized that the role of self-advocates and the parents of young children with disabilities in the fight for equal rights legislation could be strengthened if given access to the information, tools, and resources they needed to participate in policymaking process in positive and productive ways. Thus, Partners in Policymaking emerged to train families in modern day best practices of supporting individuals with disabilities and to teach the skills necessary to advocate for important and necessary changes in the system.

The goal of the program is to educate participants on how to develop positive relationships with those who make policy. The trademark Partners in Policymaking training curriculum focuses on core life areas such as Education, Employment, Residential Living and Assistive Technology. Additional topics covered throughout the program include legislation that supports core areas; approaches to advocacy and community organizing. A set of values and principles and 25 quality indicators adhere to and promote the dignity, respect, self-determination and full inclusion in society of individuals with intellectual and developmental disabilities.

Summary of the Literature Review

According to American Community Survey (ACS)² data, there are approximately 2.3 million non-institutionalized persons with a disability living in New York State (NYS) and 19% are Hispanic or Latino (of any race) and 2% are Chinese alone or in any combination of other race categories (U.S. Census Bureau, 2017). Moreover, 620,600 (27%) of the 2.3 million people with a disability in NYS speak some language other than English at home (Erickson, 2019). Among those who do not speak English at home, 56% speak Spanish and 7% speak Chinese, Mandarin or Cantonese (Erickson, 2019), which suggests that after English, Spanish and Chinese are the

¹ A Language Access Plan is a plan to ensure high quality and appropriate language assistance.

² American Community Survey (ACS) is disseminated across household nationally and annually by the U.S. Census Bureau. Anyone who lives in the U.S. can respond to the survey regardless of their birthplace or citizenship status. ACS asks individual and household level questions, such as age, income, education, language spoken at home, and disability status. Disability questions collect information on six disability type, including hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and independent living difficulty. People with intellectual and developmental disability can report more than one disability type in the survey.

two of the most common languages spoken by people with disabilities at home in NYS. Importantly, over a third (39%) of those who speak a different language at home, speak English either “not well” or “not well at all” (Erickson, 2019).

An examination of the NYS population with a Cognitive disability shows that 226,500 (27.1%) of the 608,100 persons with a cognitive disability living in NYS speak some language other than English at home. In particular, 62% speak Spanish and 7% speak Chinese, Mandarin or Cantonese. Over a third (41%) of those who speak a different language at home, speak English either “not well” or “not well at all”. The statistics suggest the importance in supporting the language needs of individuals with intellectual and developmental disabilities and their families. Table 1 shows population characteristics that were mentioned above.

Table 1. New York State Population Characteristics Related to Feasibility Study

	Individuals with Any ACS Disability	Individuals with a Cognitive Disability**
Race/Ethnicity		
Total	2,266,407	
Hispanic or Latino (of any race)	436,921 (19%)	
Chinese alone or in combination*	51,955 (2%)	
Language other than English at home	620,600	226,500
Spanish	347,536 (56%)	140,430 (62%)
Chinese (Mandarin and Cantonese)	43,442 (7%)	15,855 (7%)

Note. *Chinese alone or in combination = respondents who reported either Chinese alone or in combination of other Asian groups or race.

**Cognitive disability is measured by the following question on the ACS: Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? This question is only asked of individuals 5 years and older.

A review of the literature highlights the importance of culturally and linguistically competent programs and services given the high prevalence of people with disabilities and their family members whose primary language is not English. Previous research has documented that there is a lack of language access. Lian and Fontánez-Phelan (2001) found that although parents were comfortable with the idea of challenging school infractions, they were less confident in pursuing parental rights because of their lack of education and lack of proficiency in English. Despite knowing their rights to receiving special education and healthcare services, families are still hesitant about reaching out to these services because of their cultural and language backgrounds (Lian & Fontánez-Phelan, 2001). A review of language access in NYS found that thousands of New Yorkers with Limited English Proficiency (LEP) reported concerns also stemming from a consistent lack of competency in interpretation and translation in documents. A failed encounter

to access assistance services can sometimes lead to serious and grave results, impacting and threatening the lives of LEP individuals.

Research studies that examined experiences of LEP individuals with disabilities are consistent in that LEP individuals often report lack of access. Baker and colleagues (2010) explored the Southeast Asian perspective on developmental disabilities and the barriers to and facilitators of disability services. They found common barriers including language difficulties, lack of trust and accurate information. Southeast Asian families are reluctant to accept services and rely on government-sponsored resources because they feel families must take full responsibility for family members with disabilities, as it is the punishment for a past mistake. However, despite all these barriers, participants indicated that families are more receptive to services with education, outreach, and culturally responsive support. Issues also arise from a lack of structural and financial support. Structural barriers, such as parents not knowing how to drive so they cannot take their children to health centers. Parents also do not know how to communicate and to whom they can reach out to regarding services. Financial issues include parents being unable to afford services such as walking aids, and/or special education schools. LEP families and individuals with disabilities face several systematic barriers that affect their ability and willingness to seek support, information, and services. Therefore, it is essential to incorporate elements of CLC within Partners to support the immigrant communities are powerful drivers of local economies across the nation and strengthen New York as a whole (Nunn, O'Donnell, & Shambaugh, 2018; Treyz & Evangelakis, 2018).

Self-Assessment

The NYS DDPC and YTI recognized the importance of conducting an internal self-assessment of attitudes, practices, policies and program delivery structures and formats as an essential element of CLC program evaluation. Engaging in self-assessment at the individual and at the programmatic levels help to raise awareness and gauge the degree to which the needs and preferences of culturally and linguistically diverse groups are being addressed. Therefore, the YTI engaged in several activities for the self-assessment including attending CLC training to promote professional development and review and discuss the Partners content with YTI staff and Spanish and Chinese-speaking advisory committee members. Specifically, between January and March 2018, staff and faculty from the YTI, including the Partners in Policymaking program director, attended three on-line CLC training programs offered through The National Center for Cultural Competence at Georgetown University. Information from these webinars was cross-walked to the current NYS Partners training program format, curricula and to the core values and principles of the national Partners program model. The brief foray into the Georgetown University training confirmed that Yang-Tan staff and faculty did not have a solid theoretic knowledge of the multiple cultural and linguistic identities or the interplay between and among them.

Review of the Partners in Policymaking: The foundation for inclusive practice

The Partners in Policymaking training model is built on a set of ten core values that intentionally serve to recognize and uphold the inherent worth of all people with disabilities. A primary theoretic construct underpinning these values is the concept of “inclusion,” the meaning of which

is that everyone has a rightful place in the community and in society; that diversity is something to be valued and embraced.

- Value #1 -People with disabilities are **people first**. Partners use People First language unless the person with a disability chooses to identify through their disability.
- Value #2 - People with disabilities need and deserve **real friendships and relationships** with people who are outside the paid disability service community.
- Value #3 - People with disabilities have the **right to freedom speech**, like anyone else, and as such must have access to use any form of communication that allows that person to exercise this right.
- Value #4 - People with disabilities must have **equal access and mobility** in order to engage in active participation in community life.
- Value #5 - People with disabilities must be assured **continuity in their lives through family and neighborhood connections**.
- Value #6 - People with disabilities deserve to be **treated with dignity and respect**
- Value #7 - People with disabilities have the **freedom to choose how they want to live life and how to be supported and assisted**.
- Value #8 - People with disabilities have the **right to exercise choice and control** in all areas of their lives.
- Value #9 - People with disabilities must be able to **live in homes and communities of their choice** and receive the support that they need to do this.
- Value #10 - People with disabilities must be able to enjoy the benefits of true **productive community membership through making a meaningful contribution to civic and/or economic life**.

For the program to be fully effective, the participant must be the one who decides what each value “looks like” and have access to curricula, tools and other resources that serve their interest and need. Since program developers and facilitators have a professional and an ethical responsibility to uphold and act on the values listed above in work with every participant engaged in Partners in Policymaking training experience, it is important to critically examine the program’s agility and ability to be culturally and linguistically responsive to any/all of the program’s constituency. Thus, YTI, under guidance from external stakeholder advisory councils, engaged in a series of the evaluation process to examine the cultural and linguistic competence of the Partners program.

Stakeholder advisory group membership was accomplished by recruiting family members, caregivers and individuals with intellectual and/or developmental disabilities from Spanish speaking and Chinese speaking communities. Two distinct culturally representative advisory groups were established and tasked with reviewing select program and training content to evaluate, inform and recommend necessary modifications to the existing program and curriculum.

Each cohort advisory group began with five representatives: in the Spanish-speaking cohort, two of the five members were individuals with intellectual/developmental disabilities, one of whom completed the Partners course prior to the study. The Chinese-speaking cohort was comprised of parents of individuals with intellectual/developmental disabilities. There were no self-advocates in the Chinese cohort. One of the family members dropped out of the group before completing assigned tasks.

Focus areas for the assessment included:

1. Overall program model
2. Training curriculum
3. Program staffing
4. Program participants, current and past

Challenges to embedding principles of cultural and linguistic competence in the current Partners in Policymaking model

Recognition as an official Partners course requires the curriculum to adhere to the national model. The course design and curriculum was developed in 1987, and although it has been updated since the content represents a generalized Western perspective of disability history and uses mainstream research to define best practice for people with disabilities and their families. New York State's version of the curriculum is written in English. Theory, definition and underlying assumptions inherent in American culture may not translate easily, accurately or at all into other languages. Course format and access are based a web-based distance-learning model that requires program participants to have access to computer resources and have the skill, or be supported, to effectively navigate the learning management system platform, technology, and course resources.

The course is built on a set of core values that have an underlying assumption of self-direction, self-determination, individualism, person-centric ideologies that reflect Western cultural values. Additionally, speaking out or up to authority is a commonly accepted practice in American culture. Other cultural norms differ across these values and practices.

Feedback from Advisory Groups

Our advisory groups became instrumental in the feasibility assessment study. Chinese-speaking and Spanish-speaking advisory group members were each assigned specific content and asked to review it through the lens of cultural and linguistic competency (CLC)., To ensure continuity and help organize the feedback process, each member was provided a checklist to use to consider and record their responses. The checklist statements are as follows:

In reviewing the module, I believe...

1. The module content is presented in a way that is easy to understand.
2. The course content clearly represents the perspectives of the Chinese-speaking and Spanish-speaking community.
3. The course content addresses the advocacy needs and interests of the Chinese-speaking and Spanish-speaking community.
4. The course content uses terms that are familiar to the Chinese-speaking and Spanish-speaking community.
5. The course content provides examples, which the Chinese-speaking and Spanish-speaking community can relate to.
6. The discussion forum is an effective way to interact with others in the course.
7. The field assignments in the modules are helpful to build advocacy skills.
8. The delivery of the course uses a satisfactory variety of learning options, such as pictures, audio, and video.

The full checklist is included in the Appendix.

Some advisors shared that the contents are relevant to disability-related issues and many of them believed individuals from their communities would find the course beneficial. However, many advisors shared that participants who are individuals with disabilities and their family members from the Chinese-speaking and Spanish-speaking communities may feel disconnected from the information because there are limited cultural and linguistic components in the modules. Without cultural and linguistic components, individuals may feel low engagement and discontinue their participation in the program. One advisor stated, “[reading through the module made me] feel like a college lecture, not very engaging and not at the level of the majority of caregivers.” The following lists themes that are identified from the advisors’ feedback that aim to support cultural and linguistic competency of the Partners program. Specifically, to increase cultural and linguistic competency for Partners, the module contents should,

1. Use simpler language and explain technical terms
2. Explore different perspectives of the concepts introduced
3. Include cultural-specific examples that
 - reference Chinese-speaking and Spanish-speaking Communities
 - address the complex experience of individuals whose native language is not English
4. Be translated into Chinese and Spanish
5. Consider update to content and different learning methods

1. Use simpler language and explain technical terms

Many advisors shared that the contents and discussion questions are difficult to understand because of the language that is written. One advisor suggested,

“Reading level is very high. It may resemble a 10-grade reading level. Even with translation into Chinese, many Chinese caregivers may not be proficient in reading at this level.”

Another advisor shared,

“The complexity of the material is hard for comprehension if not educated about the basics of the way government work.”

A different advisor also stated,

“Terms and language/wording used are from an educator/professionals’ standpoint not that of the target audience.”

These comments also suggest that the issue of language might become more prominent when the module begins to discuss topical areas that are more technical and are unfamiliar to many people.

Additionally, the advisors suggest avoiding abbreviations and elaborating technical terms that are used. This may be particularly important for the Spanish and Chinese speaking communities because many people are unfamiliar with the service systems in the United States. One advisor shared,

“The basics of the material may not be easily understood because cultural differences in government relation do not apply to where the people from our community come from. The content is basically foreign to the majority of the immigrant population.”

Another advisor provided a specific example including an excerpt from Module 5: Integrated Employment. One of the paragraphs stated,

"Fear of losing SSI or SSDI benefits is a major factor keeping people with disabilities from looking for work. There are several national incentive programs in place (i.e., WIOA, Ticket to Work and ELFSMP) that are designed to support people in going to or going back to work. These and other programs underline employment as a priority."

The advisor noted that the terms, such as SSI, SSDI, WIOA, Ticket to Work, might not be familiar to everyone who lived under a different system. Having too many technical terms may overwhelm the readers, which make them feel disengaged. One of the advisors explained,

“[There are] too many technical words. As a reviewer, I am already having difficulties understand the purpose of the content, and how I would apply the information. The baseline is that I cannot understand the material.”

Therefore, the modules should ensure that all the terminologies are explained in simple language to support content comprehension.

2. Explore different perspective of the concepts introduced

The advisors feel current contents only provide single definition to the terms with distinguished values when explaining concepts. Many advisors shared that, the definitions given in the modules only represent the community to a certain extent, which they believe not everyone could relate. A modification of the content should acknowledge different perspectives of the concepts through the inter-cultural and intra-cultural lens. Specifically, the advisors explained,

“[The contents] represent part of the Chinese community because the Chinese community comes from different countries and different places that lead them to have different viewpoints.”

“Many Spanish speaking persons came from another country. Therefore, many countries have their own views about people with disabilities.”

“It does not really represent the Spanish-speaking community. There are some similarities. However, needs are very different.”

Some of the terms and concepts require further exploration, such as self-advocacy, employment, housing, person-centered, and independence, and we identified two reasons. First, many of these terms may be new to Chinese or Spanish speaking individuals. One advisor explained,

“The concept of advocacy is a newer idea for most immigrant families/caregivers as their home countries might not have the same systems in place for the general population to advocate with authorities.”

Second, there is limited cultural awareness incorporated into explaining the current systemic issues. One advisor shared, *“Some examples that I could relate to, but often the examples lost the meaning.”* Another advisor provided an example,

“The major concern on the housing issue for Chinese is that traditional Chinese families are very close, and especially they want to live with children with special needs, even when they grow up as adults. When the government is providing many housing options to families, they seem not considering that for Chinese families, their biggest wish is to live with children with special needs. In this point, I don’t think this chapter explains that very much.”

In addition, a different advisor elaborated,

“The content does not explore the complexities of pursuing an inclusive education when your native tongue is not English.”

3. Include cultural-specific examples

In order to support cultural and linguistic competence of the Partners program, the advisors brainstormed several ideas to help the program improve CLC. Many of the ideas are related to providing cultural-specific examples. Specifically, contents should refer to individuals with shared cultural and linguistic backgrounds. The advisors shared,

“It will be good to mention advocates representing the Spanish-speaking community in addition to these.”

“I think it needs more examples of people in the Spanish-speaking community. I also think it is important to understand current issues affecting Spanish-speaking communities, like poverty, deportation, family dynamics, and support system in people and more needed to help them to become strong advocates.”

“We would be happy to see more examples of our [Chinese-speaking] adult children living with parents but still can get all the support or benefits.”

“It is good to have this information in the course. I would like to see some example of how the Chinese community fight for their civil right in this session.”

Additionally, contents should include cultural-specific resources and links. The advisors shared,

“This module does not have case examples that are a directly related Chinese-speaking community, nor did it supply resources and links for us to make references to. The contents do not highlight the importance of cultural and linguistic competency.”
[Response was written in Chinese]

“As additional resources perhaps a link to special education in plain language could be provided to parents.”

4. Include Chinese and Spanish translation

It appears translating the course content would benefit both of our targeted populations. For example, people may understand the materials better, and more likely to engage in discussion. Many advisors shared the need to translate the content not only to a simpler language but also to their native language. Also, people should have the option to participate in module activities in their native language. The advisors pointed out a couple of translation issues that would be important to consider. Specifically, there might not be shared terminology in their own native language. Moreover, the same terminology might have different meanings once it is translated. The following list a couple of the example quotes:

“The language should be modified to a simpler and if possible be translated into Spanish. Keeping in mind that some terminologies are not relevant to Spanish culture and an in-depth investigation in this regard must be considered.”

“There are a lot of words in this module, and I’m not sure they could easily be translated.”

To note, these issues were emphasized more in the Spanish-speaking community, but may also be likely to apply to the Chinese-speaking community. The Partners program should consider to identify those terms and consult linguistic experts when translating the content.

5. Consider update to contents and different learning methods

Finally, the advisors noticed that some contents require updates and video should include a Spanish and Chinese subtitle. For example, one advisor shared, *“Module 4 should be updated soon because MSC soon, will be changing CCO -- Connection Management Care.”* Other advisors also suggest that the module should also include in-person lessons. *“Online modules may not be the best method to match the learning need of the Chinese speaking community. In-person facilitated discussion groups/workshops in community setting would be better than individual learning via online access.”* One of the advisors also provided an example of a communication platform (i.e., WeChat) that people use in their community, which might be a good tool to support engagement and strengthen the advocacy network.

Focus Groups

This analytical report provides a summary of the focus groups that were conducted from November to December 2018. The focus groups are a part of the comprehensive feasibility study on creating a culturally competent and linguistically accessible NYS Partners in Policymaking program (Partners) course for Spanish and Chinese speakers in New York State. The purpose of the focus groups is to explore Chinese and Spanish-speaking individuals’ experience with the online course, their needs regarding advocacy. We also examined the relevance and understanding of the course content. Specifically, we investigate three main areas in our focus groups,

1. Learning Platform - understanding participants’ learning experiences through an online platform, how participants learn and connect with others.
2. Perceived Needs – learning about linguistic and cultural needs for taking an online course and for advocating needs. Additionally, we examined challenges that participants have experiences to support their needs and strategies that participants use to access information.
3. Partners Content – assessing the cultural and linguistic competence of the current module contents. For example, we asked participants to share their understandings of key terminologies, such as advocacy.

Research methods

Five focus group interviews were conducted; two Chinese-speaking groups and three Spanish-speaking groups, involving individuals with intellectual/ developmental disabilities and family members. Four groups (i.e., two Chinese-speaking and two Spanish-speaking groups) were held

in New York City, and one Spanish-speaking group were held in Upstate New York. Participants in the study attended a two-hour focus group interview. Table 2 shows information on participant characteristics. Sixty-one participants participated in the five groups including thirty-one Hispanic/ Latino, twenty-four Asian alone, three White alone, not Latino, and three Black or African American Alone not Latino. Thirty-five participants were family members of a person with an intellectual/developmental disability, sixteen participants were a person with an intellectual/developmental disability, eight were identified as both a family member and a person with a disability, and one was identified as other without a specification.

Table 2. Characteristics of the Participants.

Characteristic	n	Percentage
Race/Ethnicity	61	
White alone, not Latino	3	4.9
Black or African American alone, not Latino	3	4.9
Hispanic / Latino	31	50.8
Asian alone	24	39.3
Gender	61	
Male	14	23.0
Female	47	77.1
Role	60	
A person with an intellectual/developmental disability	16	26.7
Family Member of a person with an intellectual/developmental disability	35	58.3
Both of the above	8	13.3
Other (please specify)	1	1.7
Location	58	
Rural	8	13.8
Urban (>2,500)	50	86.2

During the interview, participants were asked about their experience with learning through an online platform, learning needs, information needs, and experience with advocacy. Participants were also asked to review specific terms and activities that are used in the current program curriculum. Given some participants had limited English proficiency; all the materials (i.e., informed consent, recruitment email, and evaluation forms) were translated into both Spanish and Simplified Chinese. Additionally, interpretation services were provided during our focus group interviews. All the sessions were audio recorded. Data analysis entailed comparing researchers' and a note taker's notes. Themes were generated when a consensus was reached on recurring and important statements. The final report was shared with advisory members to enhance the trustworthiness of the findings. This report synthesizes and discusses critical themes generated from the focus groups. Responses are organized around the primary research areas that are Learning Platform, Perceived Needs, and Partners Content.

Summary of findings and implications

Each meeting began by providing an overview of the Partners program highlighting the different modules and features of the online course. After the overview, we asked interview questions with three foci: the learning platform, perceived needs, and Partners' contents.

Learning Platform

Computer-based/online study

Across cultural groups in upstate New York and New York City, more than half of the participants reported having a computer and stable access to the internet. Participants who did not have a computer at home or stable access to the internet noted that they could use computers and the internet at their community centers if they were to take an online course. One participant stated, "I can help to find a place with computers so that those who don't have computers at home can still come and learn the courses." Participants' comments suggest participants are able to meet minimum technical requirements (i.e., access to a computer with an internet connection) for an online course. However, participants identified a number of concerns about online courses.

Lack of technological skills

First, using computer technology was a major concern -- learning through an online platform requires a specific set of skills, and many participants reported limited computer knowledge and a need for additional assistance. Although many participants had a basic ability to type, browse the internet, or send email, they had problems installing or using software applications. For example, less than 1/3 of participants per focus group had previously taken an online course or attended a webinar. Participants who had taken an online course described problems with technical difficulties, such as software compatibility issues. One participant shared that sometimes a website is not intuitive for log-in, underscoring the importance of having a user-friendly website design for navigation. Although most participants were excited about the course, some noted that the lack of computer skills and experience in online learning might provoke anxiety because it "is scary," which might, in turn, affect the quality of learning. Their responses highlight the importance of establishing a knowledge-base and skill requirements for online learning before taking the course for both cultural groups.

Second, participants are more familiar with in-person learning and relationships, which may influence their participation and engagement in an online course. Participants who have attended an online learning session liked online learning because it is self-paced and flexible. For example, participants commented that learners could download course materials and plan a time to study based on the personal schedule. Participants also mentioned that they do not like online coursework because they cannot see other learners' faces and get timely answers to their questions. Many participants noted the value of in-person engagement and its impact on relationship building. Specifically, participants connect with each other when participating in community agency meetings, such as parent groups or other support groups. Online communications are used as supplements for face-to-face interactions. In fact, a lack of physical contact and a collaborative learning environment can contribute to low satisfaction and retention of the online course compared to traditional face-to-face courses. While participants stated they are looking forward to taking the online course, their comments suggest that individuals from both cultural and language group may benefit more from blended-learning instruction methods.

Native language preferred

With regard to language preferences for course instruction, participants unanimously agreed that the Partners program should be translated into their native language for them to learn and participate effectively. One participant shared that she prefers reading texts over listening to an auditory-only lecture because reading gives her an opportunity to comprehend in her own pace. When asked about online learning preferences, many participants shared that they learn well with a combination of reading printed words and listening to a text-to-speech option. Participants noted another ideal scenario would be video instructions with both English and Spanish/Mandarin subtitles.

Literacy consideration

Low literacy appears to be an issue for many participants. We noticed that several participants could not read and write in English. In one of the focus groups, we learned that a couple of the families could not read and write in their first language. The participants shared that they rely heavily on the support of other family members for translating and explaining messages verbally. Low literacy may reduce participants' ability to understand program materials. Therefore, text-to-speech function in natural voices, as well as the opportunity for learners to provide verbal feedback may be important.

Social communication and information access

The group discussion also explored strategies that participants use to share information and build an online community. Participants noted that most of them share information through word-of-mouth, especially in the Spanish-speaking group, instead of the use of social media to share information. Many participants are reportedly accessing the internet through a smartphone or a tablet rather than with a desktop computer. Chinese-speaking participants highlighted the use of a smartphone app called WeChat to ask questions, disseminate information, and maintain relationship and network. WeChat appears to be the dominant tool that Chinese-speaking participants use for networking. The Chinese-speaking participants shared that they use WeChat daily and receive information mostly from the interest groups that they joined on the app. Some Chinese-speaking participants also mentioned that they watch short videos on Tik Tok when they want to learn something. On the other hand, most Spanish-speaking participants used Facebook to access their social networks. Their comments suggest that Partners should consider developing a platform for learners to access the program through a smartphone or tablet. Developing social media groups may be another effective strategy for participants to sustain the learning community during the course and after the completion of the program.

Perceived Needs

Challenges on Accessing Information

Stigma, discrimination, and racism

Ability to obtain and understand information is one of the keys in being able to make appropriate and informed decisions and to participate in advocacy. Participants reported both cultural and language challenges with regard to accessing information. Their comments highlighted racial and language discrimination and stigma faced by the groups. Specifically, participants noted ethnic and language disparities in information access. Both the Spanish-speaking and Chinese-speaking groups commented on having lack of access to information compared to White and English-

speaking individuals with developmental and intellectual disabilities and their family members. One parent noted, “White people get more help than the Hispanic population; we have to fight more for our rights.” Another Latino parent commented, “They implied that I need to start spending time with White people in order to get something I need because I am Latino...Every communication [I do] should be in English because the administrator is paying closer attention to those communications in English.” One Chinese parent reportedly felt that she should learn better English. These comments suggest participants, and their communities as a whole, have experienced racial and linguistically-based discrimination in getting the information needed, and that some people might begin to internalize the blame.

In fact, this feeling of marginalization and discrimination repeatedly arose in the focus group interviews. Participants often reported feeling uncertain whether their experiences were because of their race/ethnicity, lack of English proficiency, foreign accent, or a combination of the issues. Many parents shared common experiences of being marginalized; for example, the school bus service was not accommodating to their children’s needs but provided support to their “American” (i.e., White) neighbor’s children with a similar request. Other parents shared stories, such as children were “threw out of the bus,” dropped off at wrong spots, and being inappropriately tied down in a school bus.

Failure to be provided with important information

Issues regarding lack of access to information were also revealed in comments about not being informed about service removal or provided answers to questions. A common refrain was that the services “just disappeared” or service providers “would tell us that we cannot get more support, but we don’t know why,” or “the reason given did not reflect our real situation.” Another participant shared, “my child got severely injured on the ear because of a school bus accident. The school bus driver said it is not his responsibility and the school never gives me any explanation...I think the reason why the school and the school bus didn’t give us any explanation is that they think we don’t know how to communicate.” One of the parents shared that he decided to take his children to school by himself because of a similar experience that led to feelings of distrust and frustration with the transportation services. His experience offers a description of the reasons people avoid using services or seeking support. Many comments also suggest that participants are being pushed off the system because of lack of access and support, which placed more burden on caretakers to handle issues on their own.

Language is a critical barrier. While many participants faced racial/ethnicity-based discrimination, it is clear that language is a major barrier to getting involved and having needs met. Individuals or families who do not speak or understand English are at a loss. Even when a translator is provided, the process is disruptive. For example, one participant shared a story about having to wait hours for the translator to arrive at a meeting that only lasted five minutes. In this example, the participant felt the responses they received were short and without full consideration, and their questions were not addressed adequately. The participant also questioned the competency of the interpreters, who did not seem to understand the context of the participant’s questions and did not spend the time to clarify their understanding. Many participants expressed a similar sense of frustration: they knew their rights, tried to advocate, and complied with the rules, yet they still experienced barriers, such as the example described here, which made advocating for resources impossible.

As mentioned above, participants were excited about the Partners course because they were eager to learn and advocate for their children and communities. One parent commented, “our children bear more pressure than other kids. On the one hand, they are discriminated because of their disabilities. On the other hand, they are discriminated because they are from a Chinese family.”

Information and Resources Needs

Life planning and the need for a ‘roadmap’ of practical information

In addition to the topics that are currently covered in the module, participants were interested in getting information about transition, guardianship, independent living, and services for the adult child. Many parents were concerned about their children’s future, especially after 21 years old. One parent stated, “What are they going to do if I am not around? What will happen to him?” Participants were also interested in learning how to navigate the system, and understanding the limitations of the system. Participants commented that although the Partners program sounds interesting, they are looking for practical step-by-step guidance on “How to” and “What to do when...,” such as, “What to do when an advocate is supposed to help but doesn’t help?”

We asked how participants found information and provided a situational example (i.e., “what do you do when you have a question with IEP?”). Most of the participants shared that they often find the answer through professionals, such as MSCs, DSPs, or social workers. Other ways of finding information are through word-of-mouth and search online. Chinese-speaking participants emphasized using WeChat to communicate in addition to in-person communication, whereas Spanish-speaking participants emphasized only in-person communication. Participants told us that these ways of information-finding could be time-consuming. We also observed some miscommunication of the information on disability benefits during the discussion, which suggests that participants get scattered pieces of information and need support to develop a systematic method to access information and to organize and evaluate this information.

The racial and ethnic disparity at the professional level

When asked about their need for cultural and linguistic information and resources, participants discussed issues regarding a lack of Spanish/Chinese-speaking professionals, teachers, and services that also understand the needs of people with disabilities. For example, one parent noted high staffing shortage stating, “In the school, only two people speak Spanish.” Another participant shared that when a bilingual staff member leaves his or her job, the position could go open for months. It is often the case that the new staff who fill the role does not speak Spanish/Chinese. One parent commented on lack of services that accommodate linguistic needs noting her adult son does not understand English and is non-verbal, so she cannot find any day programs for her son.

Technical terminology

With regard to the lack of linguistic support, participants also reported that they did not understand technical terminologies. That is, both they and their translators do not understand the words that service providers use. In the later section, we asked participants to share their understanding of terminology commonly used in the Partners course. In addition to linguistic needs, participants also highlighted that many teachers do not understand the needs of their children with intellectual and developmental disabilities. One parent noted that the school got

mad at her when she reached out to outside organizations for help. The participant shared, “Even when I advocate, it doesn’t matter. They get mad at me.”

Partners Course Content

Professional or technical jargon is recognized but not understood

Focus group interviews also explored the cultural and linguistic competency of the program contents. Specifically, the questions focused on participants’ familiarity with the terminology used and considerations regarding translation. Based on the suggestions of advisory committee members, we identified several frequently used key terms in the course, and we asked the participants their understandings of those terms. Additionally, we asked participants whether direct translation makes sense to them. The terms included advocacy, inclusion or community inclusion, person-centered planning, self-determination, self-advocacy, self-direction, individualized support, and supported employment.

Most participants had heard of the word advocacy, but were not familiar with other terms, or never heard of those terms. Even when the participants had heard of the terms, most of them could not describe the term. Participants agreed with the concepts behind the terms we presented, such as inclusion, and believed that they need to learn how to use the terms. For example: In the exploration of the term *Advocacy*, one Latino participant shared explained, “Self-advocacy is seen as a threat as the Latino culture is very protective and does not see people with disabilities to be able to be independent.” Another Chinese participant commented, “[Chinese] people with disabilities seldom participate in community activities.” Chinese people may practice the behavior of getting their own rights but are not used to providing a label. One participant shared, “[Advocacy] might be an action we take, but it is not a word we use very often.”

The need for simple or plain language

Moreover, we asked participants to share concerns regarding translations of terms. Chinese-speaking participants shared that, after translation, the terms sounded formal and academic, which ordinary people do not use in daily conversation. We also noted that our Spanish translators could not translate the terms directly without supplemental information. This suggests a number of challenges in translating the course, including translators’ understanding of the terms, their ability to find equivalents, and strategies to address issues, such as when equivalent terms are absent. Therefore, the process of translating the course need to include consideration of whether we translate the terms into layperson terms, technical terms, or both. Moreover, translators who are familiar with the field of disability should do the translation. It is important to also seek feedback from the stakeholders after the course is being translated.

Recommended Plan of Action

It is evident that there is a need to translate the course and related-materials into both Spanish and Chinese. Providing culturally responsive language accesses minimize communication barriers that are the result of language differences. To sum up findings from different phases of the feasibility study, we provide the following recommendations for the next phase of the project translating and improving the CLC of the PIP.

1. **Outreach and partner with cultural-specific agencies.** Cultural-specific agencies refer to organizations that are led and supported by people of the community being served. Findings

from the feasibility study highlight the critical roles that the cultural-specific agencies play in supporting Spanish-speaking and Chinese-speaking individuals with intellectual and developmental disabilities and families. For example, focus group participants frequently noted that agencies, such as Chinese-American Planning Council, (CPC), or Synergia Inc, are their go-to places whenever they have questions and needed support. These cultural-specific agencies are not only resources for language translation and strengthening the CLC of the Partners program, but also for the program outreach and marketing.

Of note, the response from participants at every focus group was overwhelmingly positive when asked if a Partners program would be valuable to their community. Invariably participants would ask the interviewers when the program would start for them. People were disappointed to learn that it may be a year or more before a translated version of the program could be offered. Thus, it is recommended that on-going contact with members of the Spanish and Chinese communities is maintained. Outreach and sustained relationship building should occur sooner than later in the rollout of the project. It would be beneficial to engage members from each community in the fall 2019 class cohort as participants and/or as advisors to curriculum and program design for translated versions.

2. **Provide technical assistance before the program starts and during the course of the training.** Many participants shared a lack of computer skills. Therefore, to ensure adequate access to the Partners program, the training should include pre-course sessions and technical assistance during the course. The pre-course session takes a proactive approach to prepare and introduce learners to the online learning platform. Partners should also offer technical assistance for technological issues during the course of learning.
3. **Include cultural brokers for Partners.** We learned from our Georgetown University training experience that cultural brokers play an essential role in promoting partnership between the cultural/language community and the training program; serving as a bridge that ensures learners understand and engage with the Partners content. We identified the following ways of including cultural brokers.
 - First, establish a partnership with community agencies that are specific to diverse communities, such as the Chinese-American Planning Council, (CPC), Synergia Inc., Ibero-American Action League, Alliance for Families with Developmental Needs, (AFDN), and Self-Advocacy Association in New York State, (SANYS). While additional evaluation on the capacity of the agencies is needed, these agencies generally work closely with families and individuals with intellectual and developmental disabilities whose English is not their first language, such as providing translated information, resources (e.g., computers), service referrals, and support groups. Community agencies have staff that speaks both languages and are located in a convenient location and that many cultural and social events were held in those agencies.
 - Second, Partners may consider developing peer-specialist positions to promote cultural brokerage. A good candidate for the peer-specialist position may be Partners' alumni of similar language group who are subject matter experts and familiar with online learning.
 - Moreover, training may incorporate a Train the Trainers model to maximize and sustain the advocacy training effort.
4. **Address cultural and linguistic barriers and awareness throughout training.** The experiences of racial and language-based discrimination were highlighted throughout the study. Participants' stories also revealed a complex issue on the impact of disability and the intersectionality of marginalized identities. Therefore, Partners training need to address

cultural and linguistic barriers including strategies to recognize and mitigate implicit biases would be vital for learners from different cultural backgrounds, and who are not native English speakers. Here we provide a list of strategies to promote cultural and linguistic competencies in Partners content development.

- Provide case examples that reflect the experience of LEP individuals with intellectual and developmental disabilities and family members/ caretakers.
 - Include examples that articulate that cross-cultural experiences, especially when the cultural norm of a given community is counter-indicated with an American value, such as the concept regarding independence/individualization.
 - Explore the strengths and challenges of the cultural and language groups.
 - Ensure key terminologies are explained in simple language and avoid using slang in the course content.
 - Develop step-by-step roadmap, strategies, and examples to guide knowledge application.
 - Providing resources that support language needs.
 - The translation should be done by professional with knowledge on the field of developmental and intellectual disabilities. Bi-lingual professionals who are subject matter masters should also review the translated products.
5. **Offer scaffold of support and multiple modes of learning options.** Scaffolding means to provide learners tools for better understanding course materials with the goal that learners will gradually be taking responsibility in developing skills and knowledge. Based on participants' feedback regarding ways of learning and availability, it is important that the course breaks tasks and information into smaller pieces with multiple opportunities to listen, read, write, and discuss and share opinions. Participants also learn better when the instruction is concrete with templates or an example for them to model.
 6. **Allow in-person learning opportunities and flexible activity assignment options.** While participants and advisors use social media tools to stay in contact with each other, they emphasized the value of meeting and engaging others in-person. Therefore, course developers may consider creating in-person meeting opportunities with a Partners graduate, such as small group discussions or projects facilitated by a graduate, and encourage learners to meet each other from their local areas face-to-face. Because the learners may come into the course with different issues and needs; for example, parents may have children at a different age with different educational/employment needs than other parents, it is important to offer flexibility in task and assignment options to maximize the learning effort.
 7. **Establish a clear understanding of course expectations and manageable learning goals.** In our focus groups with participants, we noticed that participants could lose focus on the purpose of the session. As a result, the session became a support group for many parents to share concerns and resources. There are two essential components that must be attended to making sure that the learner sees the course work as relevant to their current needs and creating the space to connect with other participants around real-life experiences. To make the course work relevant, it is important that course facilitators make sure that participants are aware of and understand the scope of the program. Reviewing graduation requirements with the group or the participant as a first step is a useful strategy. Time must be allotted for participants to engage and bond with one another during course time. This strengthens the relevance of the work and helps to form a critical network that will likely last beyond the course.

8. **Propose a clear and manageable timeline during the program translation and implementation.** In the experience collaborating and communicating with different cultural agencies, we recommend to have a bi-monthly meeting with stakeholders and lay out clear tasks including action items that are discussed during the meeting. Additionally, sending an email reminder a week before the meeting date is important. Agencies staff and advisors have also shared an appreciation of the meeting summary that we send out after our meetings. Finally, allow one-on-one opportunities for comments and clarifications after each meeting. We noticed that some of our advisors shared more when we had one-on-one Zoom meetings, which suggest some people are more comfortable to share outside of the group setting. Therefore, letting people know the availabilities of the one-on-one meeting will be helpful to facilitate communication.

Meeting Evaluation

We disseminated a meeting evaluation survey after the first advisory group and each focus group meeting. Participants were asked to rate five statements on a Likert scale from strongly agree to disagree strongly. The five statements are,

1. Meeting purpose and goals were clearly defined
2. As a focus group/ an advisory committee member, I know what is expected of me
3. The meeting discussion was facilitated in a way that makes me feel engaged.
4. The meeting created a safe environment for me to share my opinion
5. The meeting was well organized and efficient

We collected 68 after meeting survey including responses from 7 advisory committee members and 61 focus group participants. Table 3 shows the result of meeting satisfaction. The results suggest that most of the participants are satisfied with the quality of the meetings.

Table 3. Meeting Satisfaction.

Statement	% of Strongly Agree and Somewhat Agree	# of Respondents
Meeting purpose and goals were clearly defined	98%	64
As a focus group/an advisory committee member, I know what is expected of me	97%	63
The meeting discussion was facilitated in a way that makes me feel engaged	97%	62
The meeting created a safe environment for me to share my opinion	98%	62
The meeting was well organized and efficient	98%	63

Language Access Plan

A language access plan (LAP) outlines steps to ensure programs and service providers communicate information clearly and effectively to people with limited English proficiency (LEP) who may also be individuals with disabilities, or have no or low literacy skills. Development of LAP promotes cultural and linguistic competence of the program, service, or organization because it suggests these entities recognize the different communication and information access needs of people with different linguistic and cultural backgrounds.

Overview of on the process of LAP development

The current language access plan (LAP) includes four parts: (Part 1) background on NYS Partners in Policymaking (Part 2) general language access policy, (Part 3) language access self-assessment, and (Part 4) language assistance procedures. General language access policy describes the purpose of developing a LAP and operating principles that govern the implementation of the LAP to support Limited English Proficient (LEP) family members and individuals with developmental and intellectual disabilities. Language access self-assessment delineates the process of evaluating the Partners in Policymaking (PIP) program so that program participants with limited English language proficiency and disabilities can have meaningful access to the program goals and objectives. Language assistance procedures detail the “how-to” steps of language access implementation. This LAP is based on the Department of Justice’s Language Access plan template, and features of this LAP are cross-referenced with the LAP for LEP individuals for the New York State Office for People with Developmental Disabilities (OPWDD). The original documents can be found at <http://www.cpedv.org/resource-tool/language-access-resources> (Language Access Policy & Plan Template) and <https://dhr.ny.gov/sites/default/files/pdf/lep/OPWDD%202016%20Language%20Access%20Plan.pdf>

Part 1- Background on NYS Partners in Policymaking

Partners in Policymaking® is an innovative model of leadership training for people with developmental disabilities, parents, and family members. The [New York State \(NYS\) Partners in Policymaking®](#) (NY Partners) program is based on the national Partners in Policymaking® model but uses online technology to enhance and customize the curriculum. Partners complete a series of training sessions, primarily through web-based instruction.

The NYS Partners program is designed to create a platform with individuals with disabilities or family members from which to enact change at legislative and policymaking levels. Through training, Partners graduates become public figures. Acquisition of the skills, confidence, and tools to access information and make connections with influential policymakers is just one of the many benefits of becoming a New York State Partner.

NYS Partners is federally funded through the NYS Developmental Disabilities Planning Council. As a recipient of federal funds, the program is obligated to provide language assistance to any participant whose English proficiency is limited in order to ensure meaningful access to, participation in and benefit from the programs and resources offered through NYS Partners.

Part 2- General Language Access Policy

1. Policy Statement

“New York State Partners in Policymaking (NYS Partners) strives to provide its leadership and advocacy training in all eligible participants, including people with disabilities, people with limited English proficiency, and diverse cultural backgrounds. Personnel shall provide free assistance in the form of language, accommodation, and dissemination of information. All personnel will reinforce the importance of culturally and linguistically competent (CLC) accessibilities by engaging in regular CLC training and by informing members of the public that language and disability assistance services are available free of charge to advocates from diverse language and cultural backgrounds.”

2. Purpose and Authority

In accordance with Title VI of the Civil Rights Act of 1964, E.O. 13166, and the Americans with Disabilities Act, the purpose of this policy is to establish guidelines for providing culturally and linguistically competent (CLC) accessible services to Limited English Proficient (LEP) individuals with disabilities and their families. For more information, see: <https://www.lep.gov/13166/eo13166.html>

3. Definitions

- a. **Advocacy** is an activity by an individual or by a group whose goal is to influence decisions within political, social, economic and/or social systems.
- b. **Partners Candidate** is a person who has decided to take an active role in disability advocacy and to make positive change.
- c. **Cultural Competence** means that the program model protocol, course content, and resources, take into account the needs of participants with limited English proficiency, including those participants who have a disability, to ensure appropriate and equal access to respectful, meaningful and relevant course material and processes.
- d. **Linguistic Competence** is the capacity to convey information and communicate in a manner that is easily understood by diverse groups, including people with limited English proficiency and individuals with disabilities with limited English proficiency and/or limited expressive and receptive communication capacity.
- e. **Limited English Proficient (LEP) individual** means any individual whose primary language is not English, and has limited or no ability to speak, understand, read, or write English.
- f. **Diversity** is a mixed group that represents a wide range of physical and/or intellectual abilities, experience, knowledge, backgrounds, ethnicity, race, culture, customs, gender, identity, strengths and other attributes.
- g. **Leadership** is the recognition of and acting on an idea or a vision that will lead to results for the benefit of others and the self.

4. Language Data

NYS Partners program shall conduct a review of language use and cultural adaptivity every 3 years. The data we will provide include demographics of active and recent program participants, types of services used, and updates on available resources.

Part 3 - Language Access Self-Assessment

The purpose of a language access self-assessment is to evaluate the extent to which the current Partners program model and curriculum have relevance, merit and ‘transferability’ within and

across multi-cultural groups and especially those for whom English is not the primary language. Our self-assessment will use the CLC checklist, a tool for program staff and other stakeholders to use and evaluate content and delivery with respect to cultural and linguistic competency. The checklist was informed by the National Center for Cultural Competence at Georgetown University refined in consultation with advisory groups of families and individuals with disabilities (see Appendix for self-assessment checklist).

We are assessing LEP Population Language Needs. Currently, there are more than 2,238,000 New Yorkers with developmental and intellectual disabilities, and over 49,300 of these individuals come from Chinese households and 414,200 from Hispanic households. (Data Access and Dissemination Systems (DADS), 2010) This LAP will specifically serve those who have limited English proficient individuals. This Language Access Plan sets forth the actions we will take to ensure that this program will be culturally and linguistically competent for people with different cultural backgrounds that are limited English proficient to have meaningful access to services, programs, and activities.

The different ways of assessing language needs and providing assistance depend on the indicated preferred language, reading ability, and whether or not visual aid is needed. PIP users will access web-based content by selecting a preferred language for overall content. There will also be alternatives and accommodations for individuals who seek external assistance beyond web-based materials.

Part 4- Language Assistance Procedures

The following section describes the steps that NYS Partners will take to ensure all program participants have equal access to the information provided.

1. Determine the need for language assistance

- a. *All information, such as brochures, online intake forms, and any other advertising materials, will be written at the 6th grade level in English, Chinese, and Spanish and in a clear and concise form that is culturally appropriate. All disseminated information will be accessible in different learning modes to suit audience needs. NYS Program will determine language needs of the participants by (1) providing materials in English, Spanish and Chinese, (2) identifying the reading needs of the participants, and (3) informing that different modes of language assistance will be provided by the program at no cost. The contact information of translator support is included in all materials.*
- b. *NYS Partners will provide suitable language assistance to the appropriate population. We have broken down our target stakeholders into three groups to better facilitate program experience:*
 1. *LEP population with or without disability at a reading level above 6th-grade level in a language other than English*
 - i. *Users will select preferred language to view PIP online modules*
 - ii. *Users should have no trouble viewing and understanding content given above 6th-grade reading level in specified language*
 2. *LEP population with or without disability at a reading level below the 6th-grade level in a language other than English*
 - i. *Information will be provided on the website for users to access external language help to understand module contents*

- i. Brochures or flyers about language assistant services and culturally competent programs on disability advocacy
- ii. Signs posted about CLC services for individuals with disabilities
- iii. Outreach posters through disability advocacy community groups
- iv. Website content translation and accessibility

a. Notice of Language Services

- *The website will advertise translation services and different modes of content access to the individual.*
- *Translated physical materials will be distributed around community centers and advocacy groups notifying LEP individuals with a disability of their right to an interpreter.*
- *Outreach events in the form of workshops or conferences will be held intermittently in Chinese and Spanish*

i. The prohibition against using children as interpreters

Staff is prohibited from using minor children to interpret, absent emergency circumstances. Clients shall be advised of client's right to an interpreter at no cost to the client. – explain more.

Staff Compliance

b. Training

Staff will receive training on: the content of the language access policy; how to identify the need for language access services; working with an LEP and Deaf individuals; providing language accessible service in a culturally sensitive manner; working with an interpreter; and interpretation best practices.

(TIP: Contact the Interpretation Technical Assistance Resource Center for resources and assistance in training your staff.)

Internal Language Access Contacts

- c. (Identify the Language Access Coordinator for your organization)

Monitoring and Assessment

- d. *Staff shall be responsible for monitoring compliance with the organization's language access policy.*
- e. *The organization shall collect information on language use and need, including a primary language of clients; use and language of interpretation services; distribution of translated documents; frequency of contact with LEP or Deaf individuals seeking services; and referrals of LEP or Deaf individuals and the language of the referred LEP or Deaf individual.*
- f. *The organization shall conduct a review of the effectiveness of the language access policy and make changes every 3 years.*

Complaint Process

- g. *A complaint regarding the denial of language access services, or regarding the quality of language access services, including interpreters or translated materials, may be made in person, or in writing.*

- h. *The complaint should specify the date, individuals involved, and the nature of the client (i.e., the interpreter was summarizing, or an LEP individual or Deaf individual was denied services because they did not bring their own interpreter).*
 - i. *All complaints will be directed to the Language Access Coordinator.*
 - j. *The Language Access Coordinator will notify the parties within 30 days upon receipt of the complaint of the outcome.*
 - k. *Staff will notify individuals of the complaint process.*
 - l. *The complaint process will be included in the posted notification of the right to an interpreter.*
 - a. *Brochures or flyers about language assistant services and culturally competent programs on disability advocacy*
 - b. *Signs posted about CLC services for individuals with disabilities*
 - c. *Outreach posters through disability advocacy community groups*
 - d. *Website content translation and accessibility*
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- 6. The complaint process will be included in the posted notification of the right to an interpreter.*

Conclusion

The Yang-Tan Institutes of Cornell University (YTI) conducted a multiphase feasibility study in collaboration with the New York State Developmental Disabilities Planning Council (NYS DDPC) in the year 2018. The purpose of the study was to strengthen the cultural and linguistic competency (CLC) of the New York State Partners in Policymaking (Partners) program and to better support the advocacy needs of Spanish-speaking and Chinese-speaking individuals with intellectual and developmental disabilities (ID/DD) and families. Specifically, the feasibility study included a review of relevant literature, self-assessment, and a qualitative research component. A review of the literature provides a fundamental understanding of the concept of CLC, as well as research that explored the needs of limited English proficient (LEP) populations. The self-assessment involves reviewing current Partners content with internal staff and advisory committee members, who are Spanish and Chinese-speaking individuals with ID/DD and family members. The results from the self-assessment provided initial evidence suggesting the current Partners program lacks content information and linguistic competency to support LEP learners with ID/DD. The focus groups provided a thick description of LEP individuals with ID/DD and family members' experience regarding online learning and advocating. In the process of examining the CLC of the Partners program and determine the need for appropriate language translation, the YTI staff also attend training to promote CLC in the YTI. Moreover, we developed a Language Access Plan (LAP) for the Partners program that aims to support LEP learners with disabilities through a systematic guideline. Essentially, this feasibility study has taught us that becoming CLC does not only mean improving translation and interpretation services and staff; there should be measures taken to foster ongoing partnerships with regional and statewide advocacy and service organizations with strong connections to LEP populations.

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Appendix

Self-Assessment Checklist

New York State Partners in Policymaking Module Checklist

Please use this checklist to review the two modules of NYS Partners or Partners in Policymaking (Partners) for its cultural and linguistic competency (CLC).

What is CLC? CLC considers the needs of individuals with limited English proficiency (LEP) and those with disabilities that come from diverse backgrounds. A program is culturally and linguistically competent when its content provides value and significance to people of all cultures, backgrounds, and languages. Partners' curriculum should be easily accessible, understandable, and applicable to LEP individuals with or without disability. Partners' CLC programming should demonstrate staff's recognition and respect towards individuals with different cultural and linguistic needs.

We would like your feedback on the Partners course from your perspective as a member of the Chinese speaking community in New York State. We are interested in your opinion and also how other members of your community who are individuals with disabilities or family members of individuals with disabilities might feel when reviewing the curriculum. Please use this checklist to evaluate Partners program on its relevancy to your culture and the extent to which the language makes sense to you.

- The value and philosophy statement does a good job of explaining why it is important to have a culturally and linguistically competent program
 - If not, why:

Module Title:

In reviewing the module, I believe...

- The module content is presented in a way that is easy to understand.
 - If not, why:

The course content clearly represents the perspectives of the Chinese-speaking community.

○ If not, why:

The course content addresses the advocacy needs and interests of the Chinese-speaking community.

○ If not, why:

The course content uses terms that are familiar to the Chinese-speaking community.

○ If not, why:

The course content provides examples which the Chinese-speaking community can relate to.

○ If not, why:

The discussion forum is an effective way to interact with others in the course.

○ If not, why:

- The field assignments in the modules are helpful to build advocacy skills.
 - If not, why:

- The delivery of the course uses a satisfactory variation of learning options, such as pictures, audio, and video.
 - If not, why:

Now you have reviewed a couple of sample modules, we would like to learn how we could improve the Partners program to further support the learning needs of people in your community. Is there anything you would add that we did not ask or consider in the curriculum? Please provide your feedback below.

Thank you so much for taking the time to review and provide feedback on Partners in Policymaking. Your feedback is valuable and we appreciate any thoughts or concerns you may have. We are happy to work with you to further advocate for the rights and happiness individuals and family members with disabilities deserve!

Advisory Group Meeting Evaluation Form

Advisory Committee Meeting Evaluation

Q1 Welcome to Partners in Policymaking Advisory committee's meeting evaluation. By answering a brief questionnaire, you will help us understand the effectiveness of the meeting and what to improve. Thank you for your time.

Q2 Thinking about the meeting today, how much do you agree with these statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
1. Meeting purpose and goals were clearly defined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. As an advisory committee member, I know what is expected of me as an advisor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. The meeting discussion was facilitated in a way that make me feel engaged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. The meeting created a safe environment for me to share my opinion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. The meeting was well organized and efficient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q3 Is there anything you want to suggest that would improve our next meeting? If you have comments about the meeting that you did not get a chance to share during the meeting, please share them here.

Q10 Do you need an interpreter for the meeting?

- Yes
- No
- Maybe; need an interpreter stand by

Q4 Demographics

Q5 Are you:

- A person with an intellectual/developmental disability
- Family Member of a person with an intellectual/developmental disability
- Both of the above
- Other (please specify) _____

Q6 Race / Ethnicity:

- White alone, not Latino
 - Black or African American alone, not Latino
 - American Indian and Alaska Native alone
 - Hispanic / Latino
 - Asian alone
 - Native Hawaiian & Other Pacific Islander alone
 - Two or more races
 - Race Unknown
 - Other – please specify _____
 - Prefer not to say
-

Q7 Gender:

Male

Female

Other _____

Prefer not to say

Q8 Which of the following best describes the area where you live:

Rural (

Urban (>2,500)

Q9 Thank you for taking your time to complete the survey and provide us feedback. Please click **FINISH** to submit your response.

Comments by Module

Module 1-A Introduction and Orientation

Module 1-B Essential Elements of Advocacy

- Compare to Module 4, the language in 1A and 1B used better basic language
- [The discussion forum is an effective way to interact with others in the course,] only if there was no language barrier
- To a certain extent. It represents part of the Chinese community because the Chinese community comes from different countries and different places that lead them to have different viewpoints
- Chinese people are comparative conservative; they need others to advocate and encourage
- In the past, Chinese people put the disabled people in some isolated islands. Some parents even abandoned their kids. Even today still have many disabled kids are abandoned in China
- It gives people the chance to give their different opinions and get responses in a certain extent.
- After the forum and reading, everybody get some idea, it may help us to build some advocacy skills

Overall Comments

- After reviewing the modules, I think the education of the Chinese community is a need. Disabled kids parents are not willing to ask for help not only for the language and cultural

problem. Many prefer hiding their kids because they have the feeling of the discrimination of the Chinese society.

- I would like the course to have more about the Partners history, especially about how parents made historic progress about disabilities. As many Chinese people grew up in an autocratic society and culture, we don't see many examples of how those ordinary people can make such an important impact on our society. There are many historical events we can include in the course to show that

Module 2 Foundations in Partners in Policymaking

- The module content is wonderful. However, it does not show why it is important to have a culturally and linguistically competent
- I don't think it represents the perspective of the Chinese-speaking community. It does not talk the history of disability for Chinese-speaking community
- The information is not so representing the Spanish-speaking community. It may be better to provide more relevant info
- Information is more of a specific country or group. It may be helpful to hear or learn about this but expanding to Spanish speaking.
- Ideally, it will be good to mention advocates representing the Spanish-speaking community in addition to these.
- However, because of the language difference, terms are different.
- Many Spanish speaking persons came from another country. Therefore, many countries have own views about people with disabilities.
- Yes, however people may have difficulties expressing ideas in an English forum, assuming it is open for English speaker too.
- Yes, the field assignments are helpful to build advocacy
- Yes, this is great to process different learning

Overall Comments

- 我非常喜欢模块所演示的内容以及所有的链接和视频，从中学习到好多。但如果本模块是要说明文化和语言的重要性，我觉得并没有很好地被体现出来。由于文化差异，宗教信仰不同，等等，使华人的残疾史/残疾运动史，华人对残疾的认知，感受等和美国本土民众有很大的不同。如果能更有针对性地增加华人资讯，信息链接等，才有助于学习者了解华人社区的背景和需求。
- The curriculum is good. I think it needs more examples of people in the Spanish-speaking community. I also think it is important to understand current issues affecting Spanish-speaking communities, like poverty, deportation, family dynamics, and support system in people and more needed to help them to become strong advocates.

Module 3 Inclusive Education

- Reading level is very high. It may resemble a 10-grade reading level. Even with translation into Chinese, many Chinese caregivers may not be proficient in reading at this level

- The idea of less restrictive/inclusive education is great. However, for Chinese parents with language/academic limitation, tremendous work has to go in for them to advocate for more individualized services. The mainstream setting can be a big dis-service causing gaps/delays for a child who needs more restrictive/ smaller setting in the first place.
- Terms and language/wording used are from an educator/professionals' standpoint not that of the target audience
- The example of Bethany assumes a caregiver has the thorough understanding of her child in a group/classroom setting which is rare unless parents had the opportunity to make observations at school
- Feels like a college lecture, not very engaging and not at the level of the majority of caregivers
- This module does not explore the perspective of a third party (interpreter) sharing information amongst the family.
- This content does not explore the complexities of pursuing an inclusive education when your native tongue is not English.
- Honestly, it depends on the parent's background knowledge of education and their understanding of the English language.
- Depends on the partners understanding of the English language.

Overall Comments

- Online modules may not be the best method to match the learning need of the Chinese speaking community. In-person facilitated discussion groups/workshops in community setting would be better than individual learning via online access.
- As additional resources perhaps a link to special education in plain language could be provided to parents. Also, a list of parental rights could be discussed for example that a translator can be requested, the IEP/504 can be translated and given to parents prior to the CEC meeting.
 - Spanish Link:
<https://nebula.wsimg.com/6c873a70fb8b8ff2c29fd919ead45a7d?AccessKeyId=F3B51095384714C9A11D&disposition=0&alloworigin=1>
 - English Link:
<https://nebula.wsimg.com/0d5fecf61fc86b5b885f8cb7c1de2691?AccessKeyId=F3B51095384714C9A11D&disposition=0&alloworigin=1>

Module 4 Service Coordination: Case Management & Person-Centered Planning

- Module 4 should be updated soon because MSC soon, will be changing CCO -- Connection Management Care
- Content is too technical for people who just came from another country. Use basic language.
- Again, too many technical words. As a reviewer, I am already having difficulties understand the purpose of the content and how I would apply the information.
- The baseline is that I cannot understand the material
- Some examples that I could relate to, but often the examples lost the meaning.

- Filed assignments used basic language that is helpful

Overall Comments

Basic Language

Module 5 Integrated Employment

- It was an easy and good lesson for us to understand why the policy changed from segregated and shelter work option to integrated employment.
- In Chinese community, integrated employment is not common, if the disabled people must be high function and the parents believe their kids not being bullied
- Advocacy is very important to persuade the parents to step out and let the kids try
- In the past and even nowadays disabled people are under the control of some boss use different ways to get the interest from them. To explicit to use the manpower of them.
- Yes, through the forum we can discuss the advantage and disadvantage of the two policies. May be helpful to build advocacy skills.
- Yes after reading the pictures and audio, I learned the sad history of the disabled people under so-called "shelter work policy."
- If targeting low to middle class Spanish speaking population, the language should be modified to a more simpler and if possible be translated into Spanish. Keeping in mind that some terminologies are not relevant to Spanish culture and an in-depth investigation in this regard must be considered. Some, but not all individuals have earned higher education degrees from their native countries. Some may have comprehension difficulties as well as possible vision or hearing loss. Therefore, some adaptations might be needed from individual to individual taking this course.
- Module 5 talks about how important employment is for those with disability and inclusion in the workplace for them. Employment in America is viewed as person-centered as well as a person wants and needs. Latino culture in general is very protective of children with disability, and some may see employment as a form of punishment; keeping their young adults with a disability at home and close to their eyes might be a way to protecting them. Rather one believes it is the right thing for a person with a disability, the family beliefs should be acknowledged.
- Terms need to explain in their native language, also considering that the Spanish language varies from country to country. Some words may have different meanings or meaning at all depending on what country you are from.
- "Fear of losing SSI or SSDI benefits is a major factor keeping people with disabilities from looking for work. There are several national incentive programs in place (i.e., WIOA, Ticket to Work and ELFSMP) that are designed to support people in going to or going back to work. These, and other programs underline employment as a priority." (Module 5; Summary) These terms might not be familiar to all Spanish-speaking community.
- Yes, but they need to be captioned. All modules and any linked videos and materials should be translated into Spanish.

Overall Comments

Actually, both integrated and segregated policy have bad and good merits. Not everybody can find a job under the integrated policy. In the Chinese community, many disabled people are low functions and new immigrants; they do not understand English. How can these part of disabled people to get a job? I believe how good policy should be under good supervision. In the past, the sad stories we are due to lack of supervision. On the other side, stigma and discrimination are the barriers of both policies. That means education of the general public, especially in the Chinese community, is very important. That way we all the time says the needs of advocacy.

Module 6 Housing, Supported Living and Quality of Life

- The major concern on the housing issue for Chinese is as traditional Chinese families are very close, and especially they want to live with children with special needs, even when they grow up to adults, when the government is providing many housing options to families, they seem not considering that for Chinese families, their biggest wish is to live with children with special needs. At this point, I don't think this chapter explains that very much.
- We would be happy to see more examples of our adult children living with parents but still can get all the support or benefits

Overall Comments

I think the overall content is easy to understand for someone who reads at grade level. However, should someone have an SLD, DD and have difficulty reading or understanding the material, it would be helpful if there was audio available in Spanish

Module 7 Community Organizing

- I think the course has to be updated to represent Spanish speaking communities and their needs and the way they advocate. These times are different.
- I also think it will be more representative if it also includes movements or community organizing groups representing Latino families and advocates. for ex. Latinx.
- I think it does not represent the Spanish-speaking community. There are some similarities, but it definitely needs to represent a little bit more Spanish speaking community.
- It does not really represent the Spanish-speaking community. There are some similarities. However, needs are very different.
- Due to the language difference, terms are very different.
- These examples are not really relevant to the Spanish-speaking community. Again, needs are very different.
- The discussion will need to be in Spanish, this way people will be able to express themselves more openly and comfortably.
- I think there are, but it will be more effective if it represents the Spanish-speaking community
- Again, I don't think it is explaining the important to have a culturally and linguistically to Chinese-speaking community
- I spent a lot of time on the session "What is grassroots advocacy" It was a challenge for me to understand the forum discussion: "Does self-advocacy need to return to its

grassroots?” As my understanding, the self-advocacy is people with disabilities and speak up for themselves; the grassroots means people or group/organization who support and advocacy for people with disability. How self-advocacy return to its grassroots? Is it means self-advocacy groups need to join and to grassroots advocacy groups?

- At the advocacy vs. Activism session, Chinese-speaking community prefers advocacy rather than activism. However, it is good to have this information in the course. I would like to see some example of how the Chinese community fight for their civil right in this session.

Overall Comments

- Using Spanish-speaking representatives and people with disabilities is a great way to represent and convey needs and learning experience.
- 本模块的内容我也非常喜欢。尤其是 Inspiration Porn 章节。什么是真正的尊重，如何支持残障者做自己的决定而不是替他们做决定（与模块 2 中的独立运动相呼应），这种理念在华人社区中应该得到大力推广。但如同模块二一样，本模块没有华人社区的直接案例，链接可参考。也比较没有体现文化和语言的重要性。

Module 8 Legislative Process

- The complexity of the material is hard for comprehension if not educated about the basics of the way government work
- The basics of the material may not be easily understood because cultural differences in government relation do not apply to where the people from our community come from. The content is basically foreign to the majority of the immigrant population
- Many different advocacies, options, are proposed, but language barriers might prevent adequate communication
- The vocabulary is too high level and needs to be broken down in easier terms.
- The content is relatable for people who have lived here longer and had more knowledge of the law, and not for people who come more recently from a different culture /country. Also, the concept of advocacy is a newer idea for most immigrant families/caregivers as their home countries might not have the same systems in place for the general population to advocate with authorities.
- The discussion forum needs to have even more basic questions that help navigate easier, use of inclusive dialogue would be needed. In terms of the format of a discussion forum, the majority of Chinese parents are active on the social media forum “WeChat” and always share about questions they have about services and resources to one another. However, for them to answer a question or share an opinion about a learning topic, that may be a very foreign concept and less comfortable.
- It is hard to comprehend the information for caregivers and people with disabilities to follow because of the language barrier. More basic instructions need to be provided. The level of expectation and requirement of the assignments appear to be aimed at a college or graduate level student instead of an average caregiver. The wording is user-friendly, and assignment does not teach concrete advocacy skills for someone who is starting to

learn to advocacy for self or family member. From my experience and knowledge, Chinese parents highly value and are concerned the following issues when they think about advocacy: They believe their children should have the resources and support to have an education, to work (at their level) and the opportunity to make choices instead of only relying on a social security check. Even with a significant disability, parents and the individuals themselves wish to have the sense of accomplishment and pride coming from being able to contribute as a worker and be productive and to earn a living. This lifestyle will combat mental health issues that sometimes surface when a young adult with I/DD are not provided with the opportunity to be productive and have a level of independence. Ultimately, parents do wish their children to be able to contribute to society and be productive with the right amount of support.

- Very effective to use these methods however the information should be up to date.
- There are a lot of words in this module, and I'm not sure they could easily be translated.

Overall Comments

- Focusing on the basic and simple delivery of information and discussions is important for parents / caregivers and people with disabilities to fully benefit from these educational modules. Too complex terminology can cause confusion. Therefore, explanation before questions can be useful. Also, there should be workshops available.
- Will this module be delivered in Spanish?

Focus Group Protocol

Focus Group Questions

Learning Platform

Because the Partners program is an online course, we are interested in learning about what you think of taking a course online or learning through the internet, such as joining an online webinar. Please tell us,

- Do you have stable access to a computer and internet?
- How many of you have taken an online course? [Raise your hand if you have]
 - Can you describe your experience?
 - [Alternative question] What do you like or not like about the course being an online course?
- What is the best way for you to learn and engage with others for you?
 - Please explain why you prefer the methods you shared.
- How can we encourage engagement and networking of the participants during and outside of the program?
 - How do you connect with other people?

Perceived Needs

Based on the feedback from the advisory committee, we have identified the following areas of needs, which we would like to explore more in depth.

- **Language** – what language are you most comfortable with when learning and participating in discussions?
 - [Spoken: Mandarin/Cantonese; Spanish/ how different location speaks different Spanish]
 - [Written: Traditional/Simplified]
- **Availability** – if you were to take an online course, how much would you be willing or able to spend in a week? *[Provide an estimate of how much time that they will need to invest in Partners]*
 - What is the best times of day/week for you to meet online if you were to take the online class?
- **Finding Information** – How do you usually get information? *[Provide a scenario – for example, if you have an IEP question, how and where do you find help? Who do you ask for support if you have a question regarding disability needs? Could you describe the process?]*
- What information would be useful to you and your family so that you would know what to ask for, how to ask for it, and where to go to get support, resources or services?
- What FORMS of information would be useful to you and your family so that you would know what to ask for, how to ask for it, and where to go to get support, resources or services?
- What are some of the challenges you have experienced when trying to access services or when supporting your family members or friends to access services?
 - Please describe your experience.

Partners Content

Our advisors have also informed us many terms that are used in English, or in the current Partners’ modules, do not have the same meaning in Mandarin/Spanish, so we would like to explore the meaning of the following terms:

1. Advocacy
 2. Inclusion or Community Inclusion
 3. Person-Centered Planning
 4. Self-Determination
 5. Self-Advocacy
 6. Self-Direction
 7. Individualized Support
 8. Supported Employment
 9. Family Support Education
- Do you think people in your community generally familiar with these terms?
 - If not, what terms are used to describe how a person chooses where and how to live their life?

Program activities

At the end of each module, we have one activity assignment. We are interested in learning whether these activities are reasonable and realistic for you do too. I will read a couple of our activities; we would like to hear from you how you think you might complete the activity and what challenges might arise [provide an example]

OPTION 1:

Make an appointment and meet with special education folks to learn what services are provided to students with disabilities in your local elementary, middle or high school. What kinds of programs do they offer students who need special education? Where do these programs generally take place?

OPTION 2:

Make an appointment and meet with special education folks to learn what services are provided (and how) for transition planning in your local high school. How many students, on average, leave school with IEP certificates annually? Where do they end up?

OPTION 3:

Meet with community college personnel or college/university personnel to learn how students with disabilities are supported. Find out how many students with disabilities attend the school. What are the “demographics” of students with disabilities?

Focus Group Informed Consent

Focus Group Interview Consent Form

You are invited to take part in a comprehensive feasibility study on creating a culturally competent and linguistically accessible Partners in Policymaking (PIP) course for Spanish and Chinese speakers in New York State. The goal of engaging stakeholders directly from Spanish and Chinese speaking communities is to have your input inform Cornell’s internal capacity to deliver a PIP in Spanish and Chinese, and to develop a plan of action for carrying out a PIP course in Spanish and Chinese. As part of this study, you will be asked to participate in a focus group interview. The purpose of this focus group is to learn more about your needs in learning about being an advocate through an online training program.

Your involvement in the study would entail a 90 to 120 minutes of focus group interview. During the interview, our researchers will ask some questions about your learning needs, information needs, and experience with advocacy. We will also ask you to review some terms and activities that are used in the current program curriculum.

The focus group interview will be recorded for transcription purposes. The recording will be listened to by the research team only. You have the right to not to answer a question or end your participation at any point. Please note: there are no “right” or “wrong” answers to any of the questions. You can choose whether or not to participate in the focus group, and you may stop at any time during the course of the study. At the end of your participation, you will also be compensated with a \$10 gift card.

The focus group interview poses no risks greater than those encountered in day-to-day life. All of your responses will be kept confidential and reporting of results will be done in aggregate

form only. This means that only comments will be recorded, not names or other personally identifying information. In order to keep the information confidential, it is important that participants today do not share information discussed with others outside of the focus group interview.

If you have any questions about the study, you may contact the principal investigator, Carol Blessing (cjb39@cornell.edu, 518-265-3759), or Vicki Chang (vc337@cornell.edu, 607-254-8340). You will receive her contact information again at the end of the focus group interview.

By signing below, you indicate that you have read and understood the content of this form, and that you agree to participate in the focus group interview under the circumstances described.

Signature

Print Name

Date

Focus Group Meeting Evaluation Form

Focus Group Meeting Evaluation

Welcome to Partners in Policymaking focus group meeting evaluation. By answering a brief questionnaire, you will help us understand the effectiveness of the meeting and what to improve. Thank you for your time.

1. Thinking about the meeting today, how much do you agree with these statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Meeting purpose and goals were clearly defined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As a focus group member, I know what is expected of me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The meeting discussion was facilitated in a way that make me feel engaged	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The meeting created a safe environment for me to share my opinion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The meeting was well organized and efficient	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. If you have comments about the meeting that you did not get a chance to share during the meeting, please share them here.

3. Do you need an interpreter for the meeting?

- Yes
- No
- Maybe; need an interpreter stand by

Demographics

4. Are you:

- A person with an intellectual/developmental disability
- Family Member of a person with an intellectual/developmental disability
- Both of the above
- Other (please specify) _____

5. Race / Ethnicity:

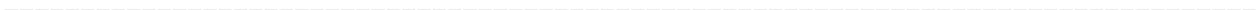
- White alone, not Latino
- Black or African American alone, not Latino
- American Indian and Alaska Native alone
- Hispanic / Latino
- Asian alone
- Native Hawaiian & Other Pacific Islander alone
- Two or more races
- Race Unknown
- Other – please specify _____
- Prefer not to say

6. Gender:

- Male
- Female
- Other _____
- Prefer not to say

7. Which of the following best describes the area where you live:

- Rural
- Urban (>2,500)



Thank you for taking your time to complete the survey and provide us feedback. Please return the form to the facilitator.