# RAISE Youth with Disabilities Needs Assessment Toolkit for Parent Centers

**RAISE**
*A SPAN Project\**

**The National Resource for Access, Independence, Self Determination and Employment (RAISE)**
**Youth with Disabilities**
**Needs Assessment Toolkit for Parent Centers**

## Introduction to the RAISE Youth with Disabilities Needs Assessment Toolkit

This toolkit is designed to help parent center leaders and staff who are seeking a systematic, best practices approach to assessing a range of needs that youth with disabilities may have.

You will learn about:

- The needs assessment process
- Advantages of conducting needs assessments
- Key steps in conducting a needs assessment
- Important considerations when conducting needs assessment for youth with disabilities

The toolkit also includes a question bank of example needs assessment questions, developed with input from youth and adults with disabilities, which may be customized for your own use, and a resource list.

## Part One: Needs Assessment

### What is a Needs Assessment?

A needs assessment is a systematic process of gathering, analyzing, and reporting information about the needs of a community, as well as its strengths and assets. A need is defined as the gap between "what currently is and what should be."[1] Needs assessments are guided by the question, "What do clients need and how can those needs be met?"[2] The purpose of a needs assessment is to use the information gained to make plans to meet those needs.[3] An effective needs assessment allows your parent center to present a more objective description of the people you serve than you would from relying only on your own impressions, experiences, and informal discussions.
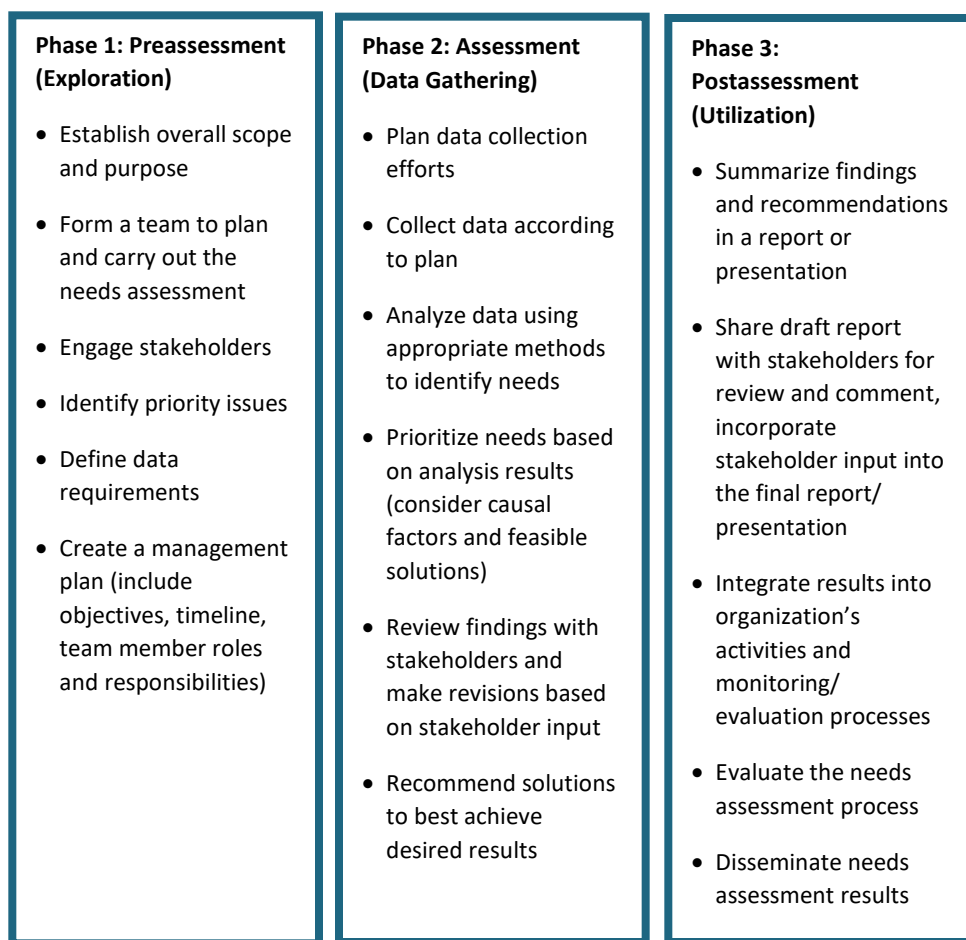
## Why Conduct a Needs Assessment?

Parent centers may have grant requirements around conducting a needs assessment, however, there are many other benefits to conducting a needs assessment, including the following list developed by Wilder Research: [4]

- **To create a common understanding of community issues.** Needs assessments help to ensure that your parent center has a common information base from which to make decisions, rather than being limited by incomplete knowledge. Having a common understanding about community issues is an important part of building consensus and working together to create solutions.

- **To create an information base for service delivery decisions.** Needs assessment allows you to make decisions about programs and services that are grounded in the needs, priorities and resources existing within the community. For example, an assessment can help your parent center make decisions about expanding or modifying services. It can also help your parent center consider alternative strategies for solving a problem or forging networks or alliances to address issues.

- **To get community involvement and support and establish joint ownership of change efforts**. Needs assessment can engage community members before decisions need to be made. Allowing residents, community organizations, businesses, schools, and others to be involved in the process may increase their investment in your program(s) and promote effective partnerships. At a minimum, community members may be involved in the needs assessment process by providing information about their perceptions of their own needs or the needs of a community. There are also benefits to including them in designing the assessment, collecting information, and using the results to guide service or community change.

- **To create a baseline picture of the community.** An assessment can create a baseline understanding of the current issues or resources facing a community. This baseline information can be used over time to identify changes and emerging issues if your goal is to promote community change. Baseline information will also be useful as you evaluate program effectiveness.[5]

## Conducting a Needs Assessment

One of the most well-known frameworks[6] for conducting a needs assessment is Witkin and Altschuld's Three-Phase Model.[7] The first phase, Preassessment (exploration) helps you prepare to implement the needs assessment. The second phase, Assessment (data gathering) involves collecting and analyzing the needs assessment data. The third, phase, Postassessment (utilization), involves setting priorities to address identified needs, communicating results, and evaluating the effectiveness of the needs assessment. The figure below provides an overview of the key tasks involved in each phase.[8]

| Phase 1: Preassessment (Exploration) | Phase 2: Assessment (Data Gathering) | Phase 3: Postassessment (Utilization) |
|---|---|---|
| • Establish overall scope and purpose<br><br>• Form a team to plan and carry out the needs assessment<br><br>• Engage stakeholders<br><br>• Identify priority issues<br><br>• Define data requirements<br><br>• Create a management plan (include objectives, timeline, team member roles and responsibilities) | • Plan data collection efforts<br><br>• Collect data according to plan<br><br>• Analyze data using appropriate methods to identify needs<br><br>• Prioritize needs based on analysis results (consider causal factors and feasible solutions)<br><br>• Review findings with stakeholders and make revisions based on stakeholder input<br><br>• Recommend solutions to best achieve desired results | • Summarize findings and recommendations in a report or presentation<br><br>• Share draft report with stakeholders for review and comment, incorporate stakeholder input into the final report/ presentation<br><br>• Integrate results into organization's activities and monitoring/ evaluation processes<br><br>• Evaluate the needs assessment process<br><br>• Disseminate needs assessment results |

(Adapted from Watkins et al., 2012)[9]

## Needs Assessment: Helpful Resources

Donaldson, J. L., & Franck, K. L. (n.d.). *Needs assessment guidebook for extension professionals*. PB 1839. University of Tennessee Extension, Institute of Agriculture. https://extension.tennessee.edu/publications/Documents/PB1839.pdf

Gupta, K., Sleezer, C.M., & Russ-Eft., D.F. 2007. *A practical guide to needs assessment*. San Francisco, CA: Pfeiffer. https://hientl.files.wordpress.com/2011/12/tnyc_a-practical-guide-to-needs-assessments.pdf InfoUse (2009). *Developing a model comprehensive statewide needs assessment with corresponding training materials for state VR agency staff and SRC members: The VR needs assessment guide*. https://rsa.ed.gov/sites/default/files/programs/vr/vr-needs-assessment-guide.pdf

NeedsAssessment.org "All things needs and needs assessment" https://na.weshareresearch.com

United States Department of Education, Office of Elementary and Secondary Education, Office of Migrant Education. (2001). *New Directors' Orientation. Comprehensive Needs Assessment.* https://www2.ed.gov/admins/lead/account/compneedsassessment.pdf

United States Department of Justice, Office for Victims of Crime (2010). *Guide to protecting human subjects.* https://www.ovcttac.gov/docs/resources/OVCTAGuides/ProtectingHumanSubjects/pfv.html

Watkins, R., Meiers, M.W., & Visser, Y.L. (2012). *A guide to assessing needs: Essential tools for collecting information, making decisions, and achieving development results*. The World Bank: Washington, D.C. https://openknowledge.worldbank.org/handle/10986/2231

Witkin, B.R. & Altschuld, J.W. (1995). *Planning and conducting needs assessments: A practical guide*. Sage: Thousand Oaks.

# Part Two: Considerations for Youth with Disabilities Needs Assessments

A review of the literature on involving youth with disabilities as partners in health research conducted by Peninsula Cerebra Research Unit (PenCRU), a childhood disability research unit at the University of Exeter Medical School[10] produced the following evidence-based considerations that are also relevant for conducting needs assessments with youth with disabilities:

## General Considerations

Involving youth with disabilities in the needs assessment process:

- Is likely to produce more useful and relevant results.

- Can have positive impacts for those involved when done well but can potentially have negative impacts if done poorly.

- Means the needs assessment is being carried out "with" or "by" youth with disabilities, rather than "to," "about," or "for" them.

## Access and Recruitment

- Successful recruitment strategies for engaging youth with disabilities in needs assessment development include the following:

  o Community venues, such as schools, hospitals, and community groups

  o Online opportunities include using online forums, social media, websites and newsletters.

  o Partnering organizations, youth workers, school and hospital staff, and parents can help to promote the opportunity to youth with disabilities.

- When advertising the opportunity, use language that is appropriate for the age and abilities of the youth with disabilities, and clearly describe the activities, level of commitment, and time requirements.

## Practical Issues

- Consider the following practical issues to support the engagement of youth with disabilities:

    o Accessible venues (for in-person interactions), regular rest periods, and refreshments are important.

    o Providing individual support for some youth with disabilities may increase their level of involvement.

    o Use available technologies and supports for youth with disabilities who use [alternative] communication [methods].[11]

    o Tailor engagement activities to the age and abilities of youth with disabilities.

    o Building trust and confidence, through honesty and providing positive feedback, is important for sustained participation.

## Potential Challenges and How to Overcome Them

- Adequate time, budget and resources are needed to provide support and build relationships.

- Provide additional training for staff, if needed.

- Offering youth with disabilities opportunities to choose and define their own roles enables them to take control.

- Parents, personal assistants, and professionals can be a barrier to youth with disabilities expressing their own views.

- A familiar communicator, care giver, or personal assistant may sometimes be necessary for youth with disabilities to participate more fully.

- Take steps to minimize adult influences on youth with disabilities expressing their own views.

- Building organizational culture and commitment to involve youth with disabilities as equal partners can help to overcome misperceptions about youth with disabilities' competency and the value of their contributions.

## Impacts of Involving Youth with Disabilities

- Positive impacts on youth with disabilities that have been reported include increased confidence and self-esteem, learning new skills, building independence, and a sense of responsibility.

- Social benefits of involvement for youth with disabilities included the opportunity for them to socialize with peers, meet new people, and make new friends.

- Needs assessment organizers need to be aware that negative impacts can occur if youth with disabilities think their involvement is not valued, or if there are not strategies in place to manage distress.

- Involving youth with disabilities has been reported to improve research, and by extension, needs assessment, by bringing their unique understanding and views to enrich the findings.

- Not including the perspectives of youth with disabilities may mean research/needs assessment is not relevant to their lives.[12]

### Needs Assessment with Youth and Youth with Disabilities: Helpful Resources

Artz, S., Nicholson, D., Halsall, E., & Larke, S. (2003). Youth friendly needs assessment. *Canadian Journal of Counselling, 37*, 4, 295-308. https://files.eric.ed.gov/fulltext/EJ822281.pdf

Bailey, S., Boddy, K., Briscoe, S., & Morris, C. (2014). *Research summary: Tips to involve disabled young people as partners in health research*. https://www.pencru.org/media/universityofexeter/medicalschool/subsites/pencru/pdfs/Review_of_involving_DCYP_Plain_english_summary_FINAL.pdf

DeChants, J., Green, A.E., Price, M.N, & Davis, C. (2021). *Measuring youth sexual orientation and gender identity*. West Hollywood, CA: The Trevor Project. https://www.thetrevorproject.org/research-briefs/measuring-youth-sexual-orientation-and-gender-identity/

Hibbert, T. (n.d.) *Firm Foundations. A Framework and tools for identifying and acting on the needs of young people*. National Youth Agency, UK. https://fdys.ie/wp-content/uploads/2016/02/Firm-Foundations-by-Tessa-Hibbert.pdf

Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Singh, I., Shikako-Thomas, K., Mirenda, P., Waddell, C., Smith, I. M., Nicholas, D., Szatmari, P., Bennett, T., Duku, E., Georgiades, S., Kerns, C., Vaillancourt, T., Zaidman-Zait, A., Zwaigenbaum, L., & Elsabbagh, M. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism: the international journal of research and practice, 23(8)*, 1882–1896. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6779014/

## Part Three: Example Questions

This section includes a collection of example needs assessment questions that may be customized for your own use. The questions do not represent one survey or needs assessment but rather provide you with options for building and customizing your own needs assessment. Many of the questions were drawn from the literature on youth/youth with disabilities needs assessment and, in some instances,

modified with input from young people with disabilities. Before embarking on any data collection (e.g., survey, focus group or interviews) with youth with disabilities, carefully consider how you will use the information you collect. Completing surveys or participating in interviews represents a commitment of time and energy on the part of youth. If you do not have a specific use for information that you're collecting, don't collect it! Simply being "interested" in a particular topic is not an adequate reason to collect data.[13]

Throughout the example questions, watch for tips identified with the lightbulb icon.

**Thank you to Everett Deibler, M.A., Ren Koloni, M.A., and Jennifer Stanton, Ed.D. for their review of and contributions to the example questions!**

> **TIP: Consider including a pre-survey statement with any survey or focus group/interview your center conducts. The following statements were suggested by Ren Koloni, M.A.**
>
> - In this survey, we are asking questions about:
>   - who you are and important parts of your life?
>   - important things about your disability or disabilities
>   - how you felt about your experience with us
>   - what you need in the future
> - Your answers will help us [understand what we need to do better, understand who we are working with, etc. - plain language goals, bullet points]
> - This survey was written with input from disabled people, but it might not always be accessible. If you have trouble accessing this survey for any reason, [contact information].
> - Only [group] will see your answers. We will not tell other people what you tell us. [Optional inclusion: It is okay if you need someone to help you fill out this survey, but they will be able to see your answers. If you ask someone to help you, make sure they are someone you trust and feel good about.]
> - This survey is anonymous. That means we will not be able to tell who you are based on what you tell us.
> - Your comfort and safety are important. For almost every question, you have the option to say, "I don't want to answer this question." You can choose this for any reason.
> - It's okay if you do not understand every question. For almost every question, you have the option to say, "I don't understand what this question is asking." [Optional inclusion: It is okay to ask someone you trust for help understanding a question.] You can also contact [contact] if you want the question to be explained differently.
> - If you need to change your answers for any reason, [how do you go back to previous questions?].
> - It's okay if you need to stop taking this survey to do something else, for any reason. [Does the program you're using save answers? Note here if so.]
> - [Prep for technical difficulty statement] Computers and the Internet do not always work perfectly. Sometimes, things go wrong when we do not expect them to go wrong. That can be distressing and scary. If something goes wrong and you feel distressed, take a break from the survey and do something that makes you feel calm.
> - Thank you for taking this survey! This will help [center] be better at helping you and other disabled youth.

## Example Survey Questions

| | |
|---|---|
| 🧩 | **Demographics** |

**Age**

How old are you?

- 12 years old or younger
- 13-15 years old
- 16-18 years old
- 19-21 years old
- 22-26 years old
- 27 years old or older

What year were you born?

**Education**

How much education have you have completed?

- Less than high school: kindergarten to 8th grade,
- Some high school but I did not complete high school
- I graduated high school or got a GED
- I went to college, but I do not have a college degree
- I went to vocational school, but I do not have a certification
- I have a certification from vocational school
- I have an Associate's degree
- I have a Bachelor's degree
- I have a graduate degree (Master's or Doctorate)
- I don't want to answer this question

## Employment

Some people are paid to do work, some people do work for free (volunteering), and some people do not work. Right now, do you work?

- I work full-time: 35 hours or more per week
- I work part time: less than 35 hours per week
- I work sometimes: I do day labor, temp work, or seasonal work
- I don't work right now, but I am looking for a job
- I don't work right now, and I am on disability
- I don't work right now, but I do volunteer
- I don't work right now, and I am not looking for a job
- None of these answers fit my situation. My situation is like this: _____
- I don't want to answer this question

## Identity

*Gender Identity*

Gender identity is how someone feels about their own gender. There are many ways a person can describe their gender identity. Which of the following terms best describes your current gender identity?

- Girl or woman (including transgender girl or woman)
- Boy or man (including transgender boy or man)
- Nonbinary, genderfluid, or genderqueer
- Indigenous or other cultural gender identity (such as two-spirit)
- I am questioning: I am still figuring out my gender identity
- I don't know what this question means
- I want to describe my gender identity in my own words. My gender identity is: _____
- I don't want to answer this question[14]

> **TIP:** When asking potentially sensitive questions about a youth's identity, carefully consider whether you need this information and how you will use it.
>
> Consider including the following language when introducing these questions:
>
> "The next few questions ask how you identify yourself. We ask these questions because the people we work with are diverse, and we want to make sure we are treating everyone equally and meeting every person's individual needs. If you don't want to answer these questions, you can choose the response that says, 'I don't want to answer this question.' Remember, we will not tell other people what you tell us in this survey."
>
> Suggested by Ren Koloni, M.A.

*Transgender Status*

When people are born, their doctors and parents assign them a gender: female or male.

Some people continue to identify with the gender they were assigned at birth. These people are cisgender.

Some people find out that they do not identify with the gender they were assigned at birth. These people might identify as transgender.

Do you consider yourself to be cisgender, transgender, or something else? Please pick the option that best describes how you think of yourself.

- I am cisgender: I identify with the gender I was assigned at birth
- I am transgender: I do not identify with the gender I was assigned at birth
- I am nonbinary or genderqueer, and I identify as transgender
- I am nonbinary or genderqueer, but I do not identify as transgender
- I am still trying to figure out my gender identity
- Not sure what this question means


*Sexual Orientation*

Sexual orientation is about who you're attracted to. There are many ways a person can describe their sexual orientation. Some people might need more than one word to describe the way they experience attraction. You can choose more than one word if more than one describes you.

- Straight or heterosexual
- Gay
- Lesbian
- Bisexual
- Pansexual
- Queer
- Asexual or ace spectrum
- Aromantic or are spectrum
- Indigenous or other cultural identity (such as two-spirit)
- Questioning: I am still figuring out my sexual orientation
- I don't know what this question means
- I want to describe my sexual orientation in my own words: _____
- I don't want to answer this question[15]


## Race/Ethnicity

What is your race? (Check all that apply)

- Indigenous, Native American, American Indian, or Alaska Native
- Asian
- Middle Eastern

- Black or African American
- Native Hawaiian or Pacific Islander
- White or Caucasian
- I want to describe my race in my own words:  _____
- I don't want to answer this question

Some people also identify as Latinx or Hispanic. Do you identify as Latino, Latina, Latinx, or Hispanic?

- Yes
- No
- I don't know what this question is asking
- I don't want to answer this question

Ethnicity is where your ancestors came from, and sometimes, the cultures you are part of. It is different from race. There are lots of ethnicities, but some examples are Chinese, Cuban, German, Puerto Rican, Guatemalan, Italian, Filipino, Vietnamese, Nigerian, Iraqi, or Ojibwe (Anishinaabe). You might identify with more than one ethnicity. You might not identify with any ethnicity.

If your ethnicity is an important part of your life, you can share it here.

- My ethnicity is:  _____
- I don't know what my ethnicity is, or I don't identify with any ethnicity
- I don't want to answer this question

> **TIP:** When asking questions about topics such as ethnicity or language, consider adapting the question content and response choices suggested here to best meet the needs of your parent center and youth audience. Explicitly naming and including the ethnic communities who live in your area and the languages that are spoken there helps support engagement for families from all backgrounds.

## Language

What language do you speak at home?

- English
- Spanish
- Vietnamese
- Korean
- Arabic
- Guajarati
- Hindi
- Russian
- French/French Creole
- Chinese
- Somali
- American Sign Language (ASL)
- Pro-Tactile American Sign Language (PTASL)
- Another language _____

**Disability**

We work with people with a lot of different disabilities. We want to know how the people we work with describe their disabilities.

Not all people use the same words to describe their disability. If the word you see here isn't quite right, that's okay. In the next question, you will have the option to use your own words to describe your disability or disabilities. Choose the words that are closest to describing your disability or disabilities.

If you have multiple disabilities, choose all of the options that you would use to describe your disabilities.

- Autism
- ADHD
- Intellectual disability
- Specific learning disability (such as dyslexia or dyscalculia)
- Speech or language impairment
- Traumatic brain injury (TBI)
- Blindness or visual impairment
- Deaf Blindness or deaf blindness
- Deafness or deafness (including partial deafness / Hard of Hearing)
- Mental health disability (such as anxiety, depression, PTSD, or schizophrenia)
- Physical disability (such as limb difference or mobility impairment)
- Chronic illness
- I have another disability that doesn't fit into any of these categories. I would describe my other disability like this: _____

**Disability Self-Identification**

Disability is complicated, and not all disabilities fit neatly into categories. Some people with more than one disability might consider one of their disabilities to be more important than the others.

Also, people use different words to describe their disabilities. For example, some people call themselves "autistic people," but other people call themselves "people with autism." Both ways to say it are okay, but it is important to respect the words that each person uses for themselves.

Because of these things, some people might want to describe their disability or disabilities in their own words. If you want to use your own words to describe your disability identity, you can do that here.

You can be as specific or as general as you want to be. You don't have to share your medical diagnoses.

This is an optional question. If you feel comfortable with how you have described your disability or disabilities already, you can skip this question.

If you don't understand this question, or if you don't know how to respond, you can skip this question.

**Government Benefits**

Some disabled people get Social Security benefits. That means that the government sends them money to help them live.

Do you get any of these benefits from the government? You can choose more than one.

- I get SSI: Supplemental Security Income. (Usually, people who get SSI have never worked before, or only worked a little.)
- I get SSDI: Social Security Disability Insurance. (Usually, people who get SSDI used to work.)
- I get food stamps.
- I have Medicare insurance. (Medicare comes from the US government.)
- I have Medicaid insurance. (Medicaid comes from the state you live in.)
- I get money from the government, but I don't know which benefits I get.
- I don't know if I get government benefits.
- I do not get government benefits.

**Contact/Contact Preferences**

Please provide your contact information: First Name:

- Last Name:
- Street Address:
- City/Town:
- State:
- ZIP Code:
- Email Address:
- Phone Number:

What pronouns do you use? (Pronouns are words we use instead of names)

- she/her
- he/him
- they/them
- ze/hir
- other: _____

Sometimes, we will send general information, like newsletters, announcements, and resources. How would you like to get this kind of information? You can choose more than one option.

- Phone
- Text
- Email
- Mail
- Social media – which ones?

Sometimes, [NAME OF PARENT CENTER] will contact you directly. How would you like for us to contact you? You can choose more than one option.

- Phone
- Text
- Email
- Mail

## Event Registration: Accommodations

Please let us know if you need any of the following accommodations to fully participate:

**Food/Dietary Needs**

Do you have any food allergies or specific dietary needs (including religious dietary needs)?

- Yes, they are: _____

- No, I don't have any food allergies or specific dietary needs.

**Communication**

Do you need anything to help you communicate with us, or to help us communicate with you? You can choose more than one.

- FM device
- All materials read out loud
- Support with writing
- Sign Language
- CART captioning
- I need something that isn't listed here. I need: _____

**Mobility**

Do you need anything to help you get around? You can choose more than one.

- Wheelchair access
- Assistance with mobility (support for walking, pushing wheelchair, etc.)
- I need something that isn't listed here. I need: _____

**Resources and Information**

Do you need anything to help you access the information we will discuss during the meeting? You can choose more than one.

- I want to read the information before the meeting
- I need digital handouts, not physical ones (these would be sent through email or online)
- Large Print
- Braille
- I need information in plain language format
- I need information in Easy Read format
- I need something that isn't listed here. I need: _____

**Parents/Personal Attendants**

Will you be bringing a parent or personal care attendant?

- Yes
- No

If yes, please provide their contact information:

- Name
- Phone Number
- Email
- Relationship to you: _____

★★☆   **Parent Center Feedback**

**Parent Center Awareness and Engagement**

How did you first learn about {NAME OF THE PARENT CENTER}?

- Website
- Personal recommendation (family or friend)
- Recommendation from a professional (service provider, clergy, etc.)
- Social media
- Presentation
- Webinar
- Resource Fair
- The way I learned about it isn't listed here. I learned about it from: _____

Which of the following {NAME OF THE PARENT CENTER} supports and services have you received?
(Check all that apply)

- I went to a training
- I went to a webinar
- I got individual support
- I got information or resources
- I got a support that isn't listed here. The support I got was: _____

How are you involved with *the* {NAME OF THE PARENT CENTER}? (Check all that apply)

- Board member
- Youth advisory member
- Presenter for training or webinars
- Staff
- Member of a youth leadership team
- I am involved in a way that isn't listed here. I am involved as: _____

If you were the Director of the Parent Center, how would you get more youth involved in our program?
For example, creating more videos for social media. _____

**Parent Center Experiences/Satisfaction**

We want to know what your experience with the Parent Center was like.

This section asks about your experience with the people who work at Parent Center.

This section works a little differently. In this section, we ask you to read each statement and decide how much you agree or disagree with it.

If you're not sure if you agree or disagree, or you don't have an opinion, you can choose "I don't know."

If the statement asks about something that didn't happen or didn't apply to your situation, you can choose "This doesn't apply to me."

*Parent Center staff . . .*

|  | Strongly disagree (1) | Disagree (2) | I don't know (3) | Agree (4) | Strongly agree (5) | This doesn't apply to me (0) |
|---|---|---|---|---|---|---|
| Treated me with respect | 1 | 2 | 3 | 4 | 5 | 0 |
| Valued my opinions | 1 | 2 | 3 | 4 | 5 | 0 |
| Valued my culture | 1 | 2 | 3 | 4 | 5 | 0 |
| Provided accommodations such as interpretation, notes… | 1 | 2 | 3 | 4 | 5 | 0 |
| Answered my questions | 1 | 2 | 3 | 4 | 5 | 0 |
| Took the time needed to listen to me | 1 | 2 | 3 | 4 | 5 | 0 |
| Helped me understand my rights | 1 | 2 | 3 | 4 | 5 | 0 |
| Helped me understand my options | 1 | 2 | 3 | 4 | 5 | 0 |
| Helped me figure out my next step | 1 | 2 | 3 | 4 | 5 | 0 |
| Gave me the information or resources I needed | 1 | 2 | 3 | 4 | 5 | 0 |

If you answered "disagree" or "strongly disagree" to any of these questions, can you tell us more about what happened?

> **TIP:** When asking a series of questions in table format (like above), consider limiting the number of questions or breaking the table into multiple sets of questions, asking no more than 3-4 questions in each table.

Do you want more support with any of the issues you discussed with Parent Center staff? Let us know here and we will get back to you.

How can Parent Center staff do things differently to be better in the future (for example, give you a list of topics that we could talk about before the meeting)?

This section asks about the information you got from the Parent Center.

Read each statement and decide how much you agree or disagree with it.

If you're not sure if you agree or disagree, or you don't have an opinion, you can choose "I don't know."

If the statement asks about something that didn't happen or didn't apply to your situation, you can choose "This doesn't apply to my experience."

| | Strongly disagree (1) | Disagree (2) | I don't know (3) | Agree (4) | Strongly agree (5) | This doesn't apply to my experience (0) |
|---|---|---|---|---|---|---|
| I plan to use the information I received | 1 | 2 | 3 | 4 | 5 | 0 |
| The information I got was helpful | 1 | 2 | 3 | 4 | 5 | 0 |
| The information I got made sense to me | 1 | 2 | 3 | 4 | 5 | 0 |
| I would recommend the parent center to a friend/ other youth | 1 | 2 | 3 | 4 | 5 | 0 |

If you don't plan on using the information you got, why not?

If you weren't happy with the information you got, why not?

How can the Parent Center make its information better in the future?

Overall, how would you rate the [services/training/resources] you received?

- Very bad
- Bad
- Okay
- Good
- Excellent

Individual Support (one-on-one)

- Very bad
- Bad
- Okay
- Good
- Excellent

**Group Training Feedback**

**Accessibility and Experience**

This section asks about your experience with group training.

Read each statement and decide how much you agree or disagree with it.

If you're not sure if you agree or disagree, or you don't have an opinion, you can choose "I don't know."

If the statement asks about something that didn't happen or didn't apply to your situation, you can choose "This doesn't apply to me."

|  | Strongly disagree (1) | Disagree (2) | I don't know (3) | Agree (4) | Strongly agree (5) | This doesn't apply to me (0) |
|---|---|---|---|---|---|---|
| The training was held at a good day/time for me | 1 | 2 | 3 | 4 | 5 | 0 |
| The training location was accessible | 1 | 2 | 3 | 4 | 5 | 0 |
| The training materials were accessible to me | 1 | 2 | 3 | 4 | 5 | 0 |
| I learned something new | 1 | 2 | 3 | 4 | 5 | 0 |
| I plan to use the information I received | 1 | 2 | 3 | 4 | 5 | 0 |
| The information was relevant to my needs | 1 | 2 | 3 | 4 | 5 | 0 |
| The training was of high quality | 1 | 2 | 3 | 4 | 5 | 0 |

What did you like best about this training?

What did you like least about this training?

What was the most important thing you learned from this training?

Please share at least one way you might use the knowledge/information you gained from this training:

What can we do differently to make this training better in the future?

Which of the following topics would you like to receive training on in the future?

- Training or education after high school
- Independent living
- Healthcare
- Transportation
- Benefits
- Disability pride
- Self-advocacy
- Systems change and advocacy with and for other people
- Becoming a leader
- Vocational Rehabilitation
- IEP
- Local services
- I want training on something that isn't listed here. I want training on: _____

## Employment Needs and Supports

Thinking about your own employment experiences and values, how important are/were each of the following in helping you to find and keep a job?

| | Not important at all (1) | Not very important (2) | I'm not sure (3) | Important (4) | Very important (5) | I didn't have this experience (0) |
|---|---|---|---|---|---|---|
| Special education as a youth | 1 | 2 | 3 | 4 | 5 | 0 |
| College education | 1 | 2 | 3 | 4 | 5 | 0 |
| Social skills or other training | 1 | 2 | 3 | 4 | 5 | 0 |
| Help looking for a job | 1 | 2 | 3 | 4 | 5 | 0 |
| Financial support from family, friends, or community | 1 | 2 | 3 | 4 | 5 | 0 |
| Support and encouragement from family, friends, or community | 1 | 2 | 3 | 4 | 5 | 0 |
| Vocational rehabilitation services | 1 | 2 | 3 | 4 | 5 | 0 |
| Access to health insurance / medical care | 1 | 2 | 3 | 4 | 5 | 0 |

| | | | | | | |
|---|---|---|---|---|---|---|
| Specific medications or treatments | 1 | 2 | 3 | 4 | 5 | 0 |
| Assistive devices / technology | 1 | 2 | 3 | 4 | 5 | 0 |
| Personal care attendant services / nurses | 1 | 2 | 3 | 4 | 5 | 0 |
| Help with transportation | 1 | 2 | 3 | 4 | 5 | 0 |
| Accommodations at work | 1 | 2 | 3 | 4 | 5 | 0 |
| Financial benefits from the government (Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), AFDC/TANF) | 1 | 2 | 3 | 4 | 5 | 0 |
| Other benefits from the government (Food stamps, housing assistance) | 1 | 2 | 3 | 4 | 5 | 0 |
| Another support not listed here: | 1 | 2 | 3 | 4 | 5 | 0 |
| other 2: | 1 | 2 | 3 | 4 | 5 | 0 |
| other 3: | 1 | 2 | 3 | 4 | 5 | 0 |

(Modified from The Lewin Group, Inc. et al., 2001).[16]


Have any of these problems made it harder for you to get a job? You can choose more than one.

- I didn't have enough education or training
- I didn't have job-related experience
- I didn't have job-related skills
- I didn't know how to look for a job
- I had a criminal record
- English isn't my first language
- There were no jobs available to me
- The employer thought I couldn't do the job because of my disability
- I didn't have the assistive technology I needed
- I didn't have the accommodations I needed
- I didn't have attendant care
- I didn't have reliable transportation
- I didn't have a reliable Internet connection
- I was dealing with mental health issues
- I was dealing with substance abuse
- I didn't have childcare
- I didn't have a place to live
- I was worried that I would lose benefits (like food stamps, money, housing, or health insurance) if I worked
- I had another problem that made it hard for me to work. My problem was: _____ [17]

What services do you need to help you get and keep the job you want? You can choose more than one response.

- Transportation
- College education
- Vocational training
- Assistive technology
- Attendant care
- Help learning how to apply for jobs (skills like writing a resume, completing an application, and interviewing)
- Help learning English
- Help finding a job
- Help asking for and getting accommodations at work
- Mental health counseling
- Substance abuse counseling
- Child care
- Affordable housing
- Home and Community Based Services
- Support on the job, like a job coach
- I need something else to get and keep the job I want. I need: _____ [18]

We want to help you access transition services. Transition services are supports that help disabled people move from school to adult life.

Have any of these problems made it hard for you to access transition services? You can choose more than one.

- I didn't have reliable transportation to get to the program
- [program] hours of operation didn't work for me
- I didn't know what services are available
- I didn't have the accommodations I needed to get services
- I was overwhelmed and didn't know where to start
- I had nobody that can help me access services
- English isn't my first language
- I had difficulties scheduling meetings with my counselor
- I had other difficulties with [program] staff
- I had difficulties completing the [program] application
- I had difficulties completing the Individualized Plan for Employment (IPE)
- I had a criminal record
- I had another problem that made it hard for me to get transition services. My problem was: _____ [19]

What supports do you need now to access transition services? You can choose more than one.

- Transportation
- Reliable Internet connection
- Help understanding what services are available
- Help understanding where to start / help making a plan
- Translation or interpretation for other languages
- Disability accommodations or assistive technology
- Help with program application[20]

Now, think about other youth with disabilities who want to get a job. What do you see as the biggest obstacles keeping disabled youth from getting and keeping the jobs they want? You can choose more than one.

- Not having education or training
- Not having job skills
- Not having enough experience
- Not knowing where to look for a job
- Family or cultural values and practices
- Having a criminal record
- Language barriers
- Poor social skills
- Not enough jobs available
- Employers' perceptions about employing persons with disabilities
- Not having disability-related accommodations on the job
- Not enough help with disability-related personal care (i.e., hygiene, feeding, etc.)
- Transportation issues
- Mental health issues
- Substance abuse issues
- Other health issues
- Childcare issues
- Housing issues
- Not knowing how to work without losing benefits
- I'm thinking of another obstacle. The obstacle is: _____ [21]

 **Resources / Services / Support Needs**

## Basic Needs

Everyone needs things in order to live well and safely. Some people with disabilities don't have access to those things.

This section asks about the things you need in order to live well and safely. These things are called needs.

In this section, we ask you to read about each need and tell us how urgent it is right now.

Urgent needs are things that you need very badly, but you aren't getting the help you need to get them. When things are urgent, you might think about them a lot. You might be worried or scared about how you are going to get them.

Things that are not urgent are things you don't worry about. These needs might not be important because you already have enough help with them, or because you can get these things on your own. They might not be important because there are other things that you are more worried about.

If you're not sure how urgent a need is, or you don't have an opinion, you can choose the midpoint (3),

If the need doesn't apply to you, you can choose "Not important/No help needed."

## Health and Mental Health

|  | Not important/ No help needed 1 | 2 | 3 | 4 | Very important/ Help urgently needed 5 |
|---|---|---|---|---|---|
| Help with getting enough healthy food. | 1 | 2 | 3 | 4 | 5 |
| Help with understanding nutrition. | 1 | 2 | 3 | 4 | 5 |
| Help making food. | 1 | 2 | 3 | 4 | 5 |
| Help with sexual health needs, information, or birth control. | 1 | 2 | 3 | 4 | 5 |
| Help with healthy relationships. | 1 | 2 | 3 | 4 | 5 |
| Help with safety. | 1 | 2 | 3 | 4 | 5 |

|  | Not important/ No help needed 1 | 2 | 3 | 4 | Very important/ Help urgently needed 5 |
|---|---|---|---|---|---|
| Help with mental health needs: help dealing with feelings like anxiety, specific mental illness, or trauma. | 1 | 2 | 3 | 4 | 5 |
| Help with accessing medical care. | 1 | 2 | 3 | 4 | 5 |
| Help with getting assistive technology (such as a mobility aid or AAC device). | 1 | 2 | 3 | 4 | 5 |
| Help with getting personal attendant care. | 1 | 2 | 3 | 4 | 5 |
| Help with connecting with other disabled people. | 1 | 2 | 3 | 4 | 5 |
| Help with dealing with substance abuse. | 1 | 2 | 3 | 4 | 5 |
| Help with learning how to advocate for myself (to medical professionals, at work, etc.). | 1 | 2 | 3 | 4 | 5 |

**Housing and Managing Life**

|  | Not important/ No help needed 1 | 2 | 3 | 4 | Very important/ Help urgently needed 5 |
|---|---|---|---|---|---|
| Help with finding and/or keeping stable, safe and affordable housing. | 1 | 2 | 3 | 4 | 5 |
| Help with staying safe. | 1 | 2 | 3 | 4 | 5 |
| Help with transportation needs like paying for public transportation, getting a driver's license, etc. | 1 | 2 | 3 | 4 | 5 |
| Help with financial needs like paying bills, budgeting or getting a bank account. | 1 | 2 | 3 | 4 | 5 |
| Help legal needs like a court case or your criminal record with. | 1 | 2 | 3 | 4 | 5 |
| Help with planning for your future. | 1 | 2 | 3 | 4 | 5 |

| | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| Help with finding a mentor or caring adult. | 1 | 2 | 3 | 4 | 5 |
| Help with childcare. | 1 | 2 | 3 | 4 | 5 |
| Help getting benefits from the government. | 1 | 2 | 3 | 4 | 5 |

**Education and Employment**

| | Not important/ No help needed 1 | 2 | 3 | 4 | Very important/ Help urgently needed 5 |
|---|---|---|---|---|---|
| Help with graduating from high school, getting a diploma, or getting a GED. | 1 | 2 | 3 | 4 | 5 |
| Help with getting into college or a training program. | 1 | 2 | 3 | 4 | 5 |
| Help with getting a job. | 1 | 2 | 3 | 4 | 5 |
| Help with keeping a job. | 1 | 2 | 3 | 4 | 5 |
| Help with getting things you need for work like clothes, equipment, or tools. | 1 | 2 | 3 | 4 | 5 |
| Help learning English. | 1 | 2 | 3 | 4 | 5 |
| Help learning about my rights at work. | 1 | 2 | 3 | 4 | 5 |
| Help learning about what accommodations I can get at work. | 1 | 2 | 3 | 4 | 5 |

**Community Supports**

Many communities offer some kinds of support for young people with disabilities.

Which kinds of support do you know for sure that your community offers? You can choose more than one.

If you're not sure that your community offers the support, don't choose that support.

- Job training services which are services that teach you how to do a job (such as job coaching, on-the-job training, or trial work experiences)
- Other education services
- Assistive technology
- Vehicle modification assistance
- Other transportation assistance
- Income assistance

- Medical treatment
- Mental health treatment
- Substance abuse treatment
- Personal care attendants
- Health insurance
- Housing
- Benefit planning assistance
- My community offers another kind of support. The support is: _____

## Example Focus Group Questions – Youth

Key topics to include when planning a focus group:

1. The **needs, interests, and personal goals** of youth with disabilities (YWD).

2. YWD **strengths** that help them meet those needs and expertise from living in their bodies and minds.

3. The **barriers** that prevent YWD from meeting those needs.

To begin you may want to start with "their story" – possible questions can include
- Can you tell me about yourself?
- Can you tell me about the services you're getting now?
- What things are really good for you right now? What things are going well?
- What things are hardest for you right now?
- What are your goals for the future, do you know how to achieve them, how do you feel about your future?

> **TIP:** Begin a focus group or interview with access reminders like the examples below:
>
> - *"You can take a break when you need to."* (Specify how to take a break in whatever setting you're using.)
> - "If you don't understand, it's okay to ask for me to say the question differently. It's okay to ask what a word means. It's okay to ask for me to repeat the question."
> - "You can take as long as you need to answer each question."
>
> Everyone should have a plan for what to do if they feel uncomfortable or stressed or need to self-soothe. The ability to pause, take a moment, and stim or breathe or think must be endorsed and encouraged by the focus group leader.
>
> Suggested by Ren Koloni, M.A.

**Supports to Sustaining Current Employment**

What do you think were the most important factors associated with your finding and getting a job?

Probes:

- motivation to look for and get a job;
- role of education, training, internships, VR, job prep/search, income support programs;
- role of family and friends;
- interests and personal goals;
- use of programs/resources not specifically for persons with disabilities;
- how were services/supports learned about, how financed/provided;
- role, attitude, and policies of employer in recruiting, providing/denying accommodations;
- family/peer/teacher expectations and perceptions of disability, employer contacts, mentors;
- delays in getting a job to avoid loss of benefits.

**Ongoing Supports Key to Keeping Your Job**

Now, I'd like to talk about the things that help you to work. Please take a moment to think about the most important services or supports you currently use, or other factors currently in your life, that help you work. What are the most important supports or factors that allow you to work with your disability?

Probes:

- role of education, training, VR, DI, SSI, Medicare, Medicaid, other public/private assistance;
- role of drugs, treatments, medical care, medical devices;
- use of programs/resources not specifically for persons with disabilities;
- how were services/supports learned about, how financed/provided;
- interests and personal goals
- management of earnings/work effort to maintain benefit eligibility;
- interruptions in employment and supports used to return to work;
- role, attitude, and policies of employer in recruiting, providing/denying accommodations;
- family/peer/teacher expectations and perceptions of disability, employer contacts, mentors;
- additional supports/services (or changes to supports you have) that would make it easier to work.

**Other Focus Group Questions**

- When young people need help and support or when they can't get it where do they go? What do they do?
- What are some of the things, the systems, the places, that are working really well?
- If you could have any resources or support, what it be?
- What are some things that you think people should know about YWDs?
- What would your version of [our program] look like?
- What things are you scared of right now? What things are you excited about / hopeful about?
- Are you connected with other people in the disability community / your community? If so, how / if not, why not?[22]

> ### Example Focus Group Questions – Families

## 1. Information Sources

I'd like to begin by having you think back to a time when you were seeking services for your youth and family. How did you learn about supports, services, or resources for your youth and family? How helpful have the following services been for your youth and family?
- Schools?
- Area Agencies?
- Your youth's doctors or people in healthcare?
- What about other families?
- Statewide organizations, supports, and resources?
- Disability communities (communities run by people with the relevant disability)?
- What would be the best way to get you information about available services?
- Have you used electronic or social media resources? How have they worked for you?
- How do you connect with other families, supports/services and resources in the community?

## 2. Services

- What services are your youth and family currently receiving?
- What other services would be beneficial to your youth and family that are not being provided now?
- What is preventing you from getting the services your youth and family needs?
- What about services for you as a parent? Such as training, family support, connecting with other parents, respite care?
- And what about crisis support services? (For your youth, for your family)

*Probes:*
"What are some things that may be preventing access to needed services?"
- Cost? Insurance coverage?
- Location / Distance?
- Awareness of what is available?
- Are services responsive/wait lists?
- language support/interpreters

## 3. Transition

We'd like to hear about how you and your youth have moved through the education and health system. Tell me about the transition you most recently or are currently experiencing. This could be the transition from early supports (early intervention) and services into the school system; or between grades/schools; or graduation. Or this could be transitions between doctors or therapists or community services.
- Where did you get information about these transitions? Did you get information early enough?
- What gaps were there – either in information or resources?
- What worked for you in moving through these transitions?

● What do you wish you would have known to help you through this?

*Probes:*
What worked well for you?
What problems did other people you know have?

## 4. Coordination

We know that youth with disabilities tend to have complex needs with education, culture, behavior, health, and social relationships. These complex needs require coordination between all of the people and agencies or organizations you and your youth deal with.
● How does this coordination happen for your family?
● Are you satisfied with the coordination you are receiving?
● What would be the best way to improve coordination?
● Who should be the central person in coordinating care? Why?

## 5. Resiliency

I'd like for you to think a minute about families of youth with disabilities
● What do you think helps families to be strong and have hope for the future?
● What could be done to support all families' strengths and dreams?
● What suggestions do you have to improve family experiences and outcomes?

## 6. Wrap Up

I'd like to thank you again for your time and the information you've provided. What else would you like to add to this conversation that we haven't touched on?[23]

**Notes**

[1] James W. Altschuld and Ryan Watkins, "A Primer on Needs Assessment: More than 40 Years of Research and Practice," *New Directions for Evaluation 144,* (2014): 5-18.

[2] James Altschuld and David Kumar, "Needs Assessment," in *Encyclopedia of Evaluation*, ed. Sandra Mathison (Thousand Oaks, CA: Sage Publications, 2005), 267-77 in Michael Quinn Patton, *Utilization-Focused Evaluation*, 4th ed. (Thousand Oaks, CA: Sage Publications, 2008), 304.

[3] Joseph L. Donaldson and Karen L. Franck, *Needs Assessment Guidebook for Extension Professionals PB 1839* (University of Tennessee Extension, Institute of Agriculture), accessed November 2021, https://extension.tennessee.edu/publications/Documents/PB1839.pdf

[4] Wilder Research, "*Types of Evaluation*," (2009). http://www.evaluatod.org/assets/resources/evaluation-guides/typesofevaluation-8-092.pdf

[5] Wilder Research, "*Types of Evaluation," 2*.

[6] For a good overview of other needs assessment models, see the Needsassessment.org website: https://na.weshareresearch.com/foundations/models/

[7] Bell Ruth Witkin and James W. Altschuld, *Planning and Conducting Needs Assessments: A Practical Guide* (Thousand Oaks CA: Sage Publications, 1995).

[8] For a more detailed description of the model and the steps involved, see Ryan Watkins, Maurya West Meiers, and Yusra Laila Visser, *A Guide to Assessing Needs: Essential Tools for Collecting Information, Making Decisions, and Achieving Development Results* (Washington, D.C.: The World Bank, 2012) https://openknowledge.worldbank.org/handle/10986/2231

[9] Ryan Watkins, Maurya West Meiers, and Yusra Laila Visser, *A Guide to Assessing Needs,* 248-253.

[10] Sarah Bailey, Kate Boddy, Simon Briscoe, and Christopher Morris, *Research Summary: Tips to Involve Disabled Young People as Partners in Health Research*, 2014. https://www.pencru.org/media/universityofexeter/medicalschool/subsites/pencru/pdfs/Review_of_involving_DCYP_Plain_english_summary_FINAL.pdf

[11] The authors used the phrase "non-verbal communication" in the original text.

[12] Sarah Bailey, Kate Boddy, Simon Briscoe, and Christopher Morris, *Research Summary*.

[13] Limiting data collection and use of people's personal data to the minimum that is directly relevant and necessary to accomplish a specific purpose is generally recognized as an important component of data privacy, laws, principles, ethics, and best practices.

[14] Modified from Jonah DeChants, Amy E. Green, Myeshia N. Price, and Carrie Davis, *Measuring Youth Sexual Orientation and Gender Identity* (West Hollywood, CA: The Trevor Project, 2021). https://www.thetrevorproject.org/research-briefs/measuring-youth-sexual-orientation-and-gender-identity/

[15] Modified from Jonah DeChants et al. *Measuring Youth Sexual Orientation*.

[16] The Lewin Group, Inc., Berkely Policy Associates, and Cornell University, *Research on Employment Supports for People with Disabilities: Summary of the Focus Group Findings* (2001).

https://aspe.hhs.gov/reports/research-employment-supports-people-disabilities-summary-focus-group-findings-0

[17] Modified from Rachel Anderson, Chaz Compton, and Melissa Kronberger, *State of Idaho Division of Vocational Rehabilitation Comprehensive Statewide Needs Assessment Report* (San Diego State University Interwork Institute, 2020). https://vr.idaho.gov/wp-content/uploads/Idaho-2020-CSNA-Report-.pdf

[18] Modified from Rachel Anderson, Chaz Compton, and Melissa Kronberger, *State of Idaho Statewide Needs Assessment Report*.

[19] Modified from Rachel Anderson, Chaz Compton, and Melissa Kronberger, *State of Idaho Statewide Needs Assessment Report*.

[20] Modified from Rachel Anderson, Chaz Compton, and Melissa Kronberger, *State of Idaho Statewide Needs Assessment Report*.

[21] Modified from Rachel Anderson, Chaz Compton, and Melissa Kronberger, *State of Idaho Statewide Needs Assessment Report*.

[22] Matthew Aronson Consulting, *Youth and Young Adults Experiencing Homelessness on Cape Cod, Martha's Vineyard, and Nantucket: A Community Needs Assessment*, 2019. https://www.bchumanservices.net/library/2019/09/Community-Needs-Assessment-for-YYA-Homelessness-on-the-Cape-and-Islands-9-9-19-_PDF.pdf

[23] Modified from New Hampshire Council on Autism Spectrum Disorders, Special Medical Services, Child Health Services, New Hampshire Family Voices, and New Hampshire Leadership Education in Neurodevelopmental Disabilities, *NH Statewide Autism Spectrum Disorder (ASD) Needs Assessment, 2014*. http://nhfv.org/wp-content/uploads/2013/09/ASD-Needs-Assessment-2014-Final.pdf