Illinois Health Care Provider Quick Resource Guide:
A resource for developmental and behavioral health screenings and referrals of young children

Endorsed by:

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Author by the Beyond Coverage Coalition (EverThrive Illinois, Legal Council for Health Justice, and Sargent Shriver National Center on Poverty Law) with generous support from Grand Victoria Foundation, Irving Harris Foundation, Robert R. McCormick Foundation, Polk Bros. Foundation, Prince Charitable Trusts, and David and Lucile Packard Foundation. For the most recent version of this Guide go to: https://legalcouncil.org/illinois-child-developmental-screening-guide/
Why Screen?

**One in four children is at risk of a developmental delay.**¹ You are uniquely well-situated to help families celebrate milestones and to catch any developmental or behavioral delays and concerns. Early identification can lead to timely therapeutic interventions that will promote the wellbeing of children and their families, and can avoid later challenges in school and social-emotional difficulties.²

**Validated screening tools identify three times as many children in need of services** compared to provider reliance on clinical judgment alone.³ Combining developmental surveillance and periodic screening with a validated tool increases the opportunity for identification of delays in early development.

**Early Intervention and supportive resources are important.** This Quick Resource Guide (Part 1 & Part 2) is intended as a handy reference for Illinois health providers to keep at their fingertips for use in referring patients to Early Intervention and other services.

**Children are entitled to screenings.**⁴ Developmental and behavioral screening is an important part of the Illinois Department of Healthcare and Family Services (HFS) Medical Assistance Program’s EPSDT services.⁵ A new state law,⁶ for which the Illinois Department of Public Health is developing implementation rules, requires developmental and social-emotional screening to be included in the school health exam, given to all children before enrollment in child care and preschool/nursery school, during a child’s kindergarten or first grade year, upon entering sixth and ninth grades, and whenever out of state students enroll in Illinois schools.⁷ Providers of health care to infants must also offer maternal depression screening to mothers.⁸

Screening is covered under the Affordable Care Act as a preventive service,⁹ and is billable to Medicaid, MCOs, and private insurance, with most accepting codes **96110** (developmental screens) and **96127** (behavioral screens). Maternal depression screening at an infant visit may be billed to **96161** in some plans, or to **96127** with an HD modifier.¹⁰
When to Screen

At every health supervision visit, conduct developmental surveillance (ask about parents’ concerns, obtain a developmental history, make observations of the child, identify risk and protective factors, and document the findings). Check the child’s progress in fine and gross motor skills, communication, problem solving, and social-emotional development, and discuss all milestones and strengths with the parent. Offer anticipatory guidance to support emerging skills.

At 9, 18, and 30 months, or whenever surveillance reveals a concern, conduct developmental screening using formal, validated screening tools. Providers can screen at any visit, including visits past 30 months, if either the parent or the health provider identifies a concern.

At 18 and 24 months, screen all children for autism spectrum disorder. In addition, the American Academy of Pediatrics (AAP) recommends that children be screened for behavioral and emotional concerns with formal, validated tools at regular intervals beginning in the first year of life.

At 1, 2, and 6 months, conduct screening for maternal depression.

What Tool to Use

Providers may bill for up to two screening tools per visit. A screening tool consists of questions regarding the child’s body movements, how they use and understand language, how they play and solve problems, their behaviors and emotional responses, and how they interact with other people. Practices may choose any tool from the list of age-appropriate, validated, standardized questionnaire tools approved by HFS for reimbursement. Birth to 5: Watch Me Thrive! also provides a useful compendium of screening resources.

Some questionnaire tools are filled out by parents or caregivers, and others by healthcare professionals. The healthcare provider scores the answers and discusses the children’s screening results with the parent.

Additionally, a child’s Head Start, child care center, or home visiting service may conduct developmental screening. Encourage parents to ask those providers to share their screening results with you as well. You may receive a Care Coordination Form from the home visiting staff or child care provider if screening information is shared with you.
What Happens Next?

The provider may decide to:

- Continue routine developmental screening and surveillance, or
- Suggest another screening soon after the visit to confirm and further discuss the results, or
- Refer the child immediately to supports and resources in areas of development that are delayed or at risk of potential future delay. Referrals to Early Intervention should take place within five working days after a potentially eligible child is identified.

If the results of the screening and surveillance indicate a potential developmental concern, further developmental and medical evaluation needs to follow without delay. It may be appropriate to refer the child to a developmental pediatrician or other specialist, as well.

Additional Screening Resources:

- For more information and how-to podcasts, visit the AAP’s [Screening, Technical Assistance Resource (STAR) Center website](https://www.aap.org/en-us/policy-center/screening-technical-assistance-resource-star-center).  
- An Illinois [Care Coordination Toolkit](https://www.dhs.state.il.us/dhscms/bcp/care-coordination-toolkit) produced by DHS, HFS, and the Illinois Chapter of the AAP (November 2015) is available on the [HFS website](https://www.hfs.illinois.gov). In addition, Illinois AAP offers an online training on [Developmental Screening and Referral](https://www.illinoischildren.org/early-intervention-content-development-screening-referral).  
- CDC developed an app to assist parents in tracking their child’s milestones. The [Milestone Tracker app](https://www.cdc.gov/milestone_tracker/) can be downloaded on an Android or iOS phone.

*See Part 2 for list of post-screening referral resources.*
Centers for Disease Control (CDC) Algorithm
Be Proactive. Parents may not ask for a screening, may be unfamiliar with the concept of screening, or may be reluctant to have their child screened due to personal or cultural beliefs or concerns. Because development is viewed differently in every culture it is important to explain the screening, results, and any developmental delays to families in a way that is open and considerate of their perspective. Parents and caregivers may also worry that delays are the result of bad parenting, and may need you to reassure them if a screening shows a delay.

**How can I help families?**

**Explain that a screening is not a diagnosis:**
Screening is a way to understand how the child's communication, thinking and problem solving, body movement, and social-emotional skills are coming along and if there are any skills that might need a little extra support.

**Ask clarifying questions about parental expectations of development:**
This can help you better understand what the parent may report on the screening and why, as well as help you frame concerns, delays, and milestones in a way that makes sense to the family and recognizes cultural influences on familial experience.

**Provide clear information regarding next steps:**
This can include additional screening or referrals, as well as continuing surveillance to ensure the child’s development stays on track.

**Always be sure to...**

- Allow parents time to ask questions and voice concerns
- Highlight a child’s strengths and celebrate milestones
- Connect families to appropriate resources and referrals
Referral Resources

- Early Intervention (ages 0-3), Early Childhood Special Education (ages 3-5)
- Early Head Start
- WIC
- Home visiting
- High quality child care
- Other community resources.

Screening is only the first part of the process. The referral process is essential to helping children and families reach optimal developmental outcomes. Depending on the outcome of the screening, the child may benefit from referral to one or more types of services spanning from Early Intervention to high quality child care programs. This resource outlines common services.

What is Early Intervention (EI)?

EI’s mission is to ensure that families who have a child, birth to three, with developmental delay, diagnosed disability, or risk of substantial delay receive resources and supports that assist them in maximizing their child's optimal development, while respecting the diversity of families and communities.

El Services may include

- Assistive Technology
- Family Training and Support
- Nursing
- Physical Therapy
- Social Work
- Vision
- Audiology/Aural Rehabilitation
- Health Consultation
- Nutrition
- Psychological Services
- Speech Language Pathology
- Developmental Therapy
- Medical Diagnostics
- Occupational Therapy
- Service Coordination
- Transportation Services
Children eligible for EI services include those under three years of age who fall in one of three categories:

1. Child diagnosed with a medical condition\(^{20}\) typically resulting in developmental delay

2. Child experiencing a \(30\%\) delay in one or more of the following areas:
   - Cognitive
   - Physical
   - Social or Emotional
   - Adaptive
   - Communication

3. Child at risk of substantial developmental delay because:
   - A parent has a diagnosed mental illness or serious emotional disorder defined in the DSM 5, or a parent has a developmental disability.

Or child is at risk of substantial developmental delay due to presence of three or more of the following factors:

- Current alcohol or substance abuse by primary caregiver
- Primary caregiver who is currently less than 15 years old
- Current homelessness\(^{21}\) of child
- Indicated case of abuse or neglect that did not result in the child being removed from those circumstances
- Chronic illness of primary caregiver
- Alcohol or substance abuse of mother during pregnancy with the child
- Primary caregiver with a 10th grade education or less, unless that level is appropriate given the caregiver’s age
How do I refer to Early Intervention?

- Use the [Standardized Illinois Early Intervention Referral Form](#) (must access using Internet Explorer; see page 12). Full completion of the form provides the EI team with information helpful to determine appropriate evaluations and services for the child. Send the form by FAX to the appropriate Early Intervention Child and Family Connections office (CFC) based on the child’s ZIP Code. The correct CFC can be located through [the DHS Office Locator](#).

- If applicable, under “Suspected developmental delay” indicate ALL potential areas of concern.

- A referral can be made without a specific diagnosis.

- Illinois requires the referral to be sent within five business days after screening or identification.

- Once the patient is referred, Early Intervention must contact the family within two business days. The CFC will coordinate evaluations and assessments of the child in five domains: cognitive, physical, social-emotional, communication, and adaptive skills, and then determine eligibility for services. An Individualized Family Service Plan (IFSP) for eligible children must be created within 45 days of referral.

- IFSP plans are developed with family participation and embed strategies around family routines. Services must begin within 30 days.

- Services should take place in the child’s natural environment, including the home, child care, or a community setting where child spends time with typically developing peers.

- In addition to service coordination families may receive an array of services. You may want to ask the family for a copy of their IFSP which will detail the frequency and type of EI services. If the family has completed the Authorization to Release Information to Referral Source on page 2 of the Standardized Form, or otherwise provided consent, then you may obtain the IFSP directly from the CFC.

- Children with specific medical risks may require further medical evaluation not offered by EI.

- Some children may qualify for other benefits such as [Supplemental Security Income](#) (SSI).

- A family may self-refer to Early Intervention by calling their local [Child and Family Connections Office](#). However, if a family self-refers, the provider will likely not receive the Referral Fax Back forms that provide primary care provider with referral status, eligibility, and service information (see next page).
Tips on Filling out the EI Referral Form:

- The best way to refer to EI is by completing the Standardized EI Referral form. If possible, include this form in the electronic medical record to ensure easy access. The form is available online (access using Internet Explorer) and consists of two pages.
- Please have parent sign the Authorization to Release Information and additionally attach any relevant screening results or diagnostic information.
- Fax the form to the appropriate CFC office. The CFC will follow-up by sending you a two-part Referral Fax Back Form (pages 14-15). Part 1 lets you know status of contact with the family. Part 2 lets you know eligibility and service information.
- If faxing is impossible, you or the parent may call the CFC directly.
- Please see UpstreamHealth for quick access to EI referral information/forms and advocacy tips.

When to Refer to the School District:

- If a child is 33 months old, refer to both Early Intervention and also to the local school district for evaluation to ensure a smooth transition to early childhood special education services. If a child is within 45 days of their third birthday, refer directly to the local school district instead of Early Intervention.
- Beginning at the age of three, children with developmental delays and disabilities can receive services through their local school district. A Standardized Early Childhood Special Education Referral Form is being developed to make referrals to schools for special education evaluations under Part B of the IDEA. In the meantime, it is best to make a referral to the school district via a letter that is also signed by the parent. Also, be sure to get a signed authorization for release of information from the parent to be able to communicate with the school district and/or the child’s local school.
Additional Resources for Children and Families

If there are developmental concerns, but a child does not meet the eligibility requirements for Early Intervention, finding a high quality early learning setting or home visiting program to support the child’s development is important. Children receiving EI can also benefit from these programs. The American Academy of Pediatrics updated their policy statement in August 2017, supporting the use of quality early education programs as vital learning environments that have a “lifelong impact on health.”

Head Start and Early Head Start

Head Start is a federal program that focuses on increasing school readiness of children from three to five years of age. While it is primarily focused on providing care to children from low-income families, a certain percentage of participants may come from families with incomes above the federal poverty line. Head Start programs focus on promoting development in a variety of areas such as language and social-emotional development.

*Early Head Start is available for eligible children birth through three years of age.* Both Head Start and Early Head Start are based on eligibility criteria and a family must call to see if they qualify. The family may go online and find the closest program in their area and apply directly or call 1-866-763-6481.

ExceleRate Illinois

ExceleRate Illinois helps families identify child care centers, school based preschools, and licensed home based child care providers that meet state quality standards for developmentally focused early learning. Health providers may refer a family to the ExceleRate website (http://www.excelerateillinois.com) or help them search the site to find the closest program to them. Head Start and Early Head Start programs are included in the ExceleRate listing.

Child Care Assistance Program

The subsidized child care program (known as CCAP) provides assistance for child care for working families at or below 185% of the federal poverty level. The program also provides services to working families receiving Temporary Assistance for Needy Families (TANF) and non-TANF families that need child care assistance to participate in work, education, or training activities. Illinois has a statewide network of Child Care Resource & Referral (CCR&R) agencies that are CCAP points of entry. Families should be referred to the CCR&R that serves the region in which they live for any questions about eligibility or for information about finding care for their children. Call 1-877-202-4453 (toll-free) or visit INCCIRA.
Home Visits
Home visiting programs are an additional source of support for families, providing services to pregnant women and parents of children from birth to age five. In these voluntary, free programs, parent coaches visit the home to help parents create safe, stimulating home environments, model positive and language-rich relationships, and ensure families are connected to medical, dental, mental health, nutrition, and other supports. Depending on the community, home visiting programs may be offered through school districts or community organizations. Program models include Early Head Start, Healthy Families America, Nurse Family Partnerships, Baby Talk, and Parents as Teachers. The federal Maternal Infant Early Childhood Home Visiting program (MIECHV) provides support for many of the programs in Illinois. To locate a home visiting provider, go to http://igrowillinois.org/find-a-program/.

Supplemental Security Income (SSI)
Low-income children under 18 who have serious medical conditions or conditions that cause severe functional limitations may be eligible for children's SSI. A parent can apply for SSI disability benefits online, or by calling 1-800-772-1213.

Additional Resource for Providers: UpstreamHealth.org
The goal of UpstreamHealth is to connect providers to the social, economic, and health resources that may benefit their patients. UpstreamHealth provides summaries of these resources as well as links to the forms needed to obtain them and additional information about each. Most of the resources referenced in this Resource Guide are included on UpstreamHealth. If in need of more information about these services or any others such as housing assistance, school enrollment, requests for special education evaluations, or children’s waivers, refer to UpstreamHealth. The website is regularly maintained by the Legal Council for Health Justice.

** All information in this document has been updated as of October 2018
Standardized Illinois Early Intervention Referral Form

Please complete Sections 1 through 6 of this form to refer a child to Early Intervention (EI) for eligibility determination.

### Section 1. Child Contact Information

<table>
<thead>
<tr>
<th>Child Name:</th>
<th>If the child is known by another name enter it here:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Child Age:</td>
</tr>
<tr>
<td>Gender: Male □</td>
<td>Female □</td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>City:</td>
<td>State:</td>
</tr>
</tbody>
</table>

| Type of Insurance Coverage: | Medicaid □ | Private Insurance □ | None □ |

Parent/Guardian Name: Relationship to Child: 

| Primary Language: | Home Phone: | Other Phone: |

Alternate or Emergency Contact Person: Phone Number: 

### Section 2. Reason(s) for Referral

Reason(s) for referral to EI (Please check all that apply): 

- [ ] Identified physical or mental condition (List of Medical Diagnoses or type URL [http://www.dhs.state.il.us/page.aspx?item=82917](http://www.dhs.state.il.us/page.aspx?item=82917)). If yes, please describe: 

- [ ] Suspected developmental delay based on objective screening (please name tool(s)): 


  Comments: 

- [ ] At risk conditions (e.g., diagnosed caregiver condition, other risk factors to child) (List of At Risk Conditions or type URL [http://www.dhs.state.il.us/page.aspx?item=96963](http://www.dhs.state.il.us/page.aspx?item=96963)), please describe: 

- [ ] Other, (Please describe): 

- [ ] Family is aware of reason for referral 

### Section 3. Referral Source Contact Information

If the child's Health Care Provider is making the referral, skip Section 3 and complete Section 4. If an Early Childhood Program is making the referral, check here. NOTE: Any agency may use this referral form. 

Name of Agency Making Referral: 

Address: 

City: | State: | Zip Code: 

Office Phone: | Office Fax: 

E-mail: | Contact Person at Referral Site: 

### Section 4. Health Care Provider Contact Information

Agencies listed in Sec. 3, please complete Sec. 4 (with parental consent) to assure child's Health Care Provider is informed of referral. 

Name of Child's Health Care Provider: 

Street Address: 

City: | State: | Zip Code: 

HFS 650 (R-3-18) | IOC18-0441 (CD) 

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Section 5. Early Intervention CFC Office Referral Location

FAX form to the CFC where the child is being referred: CFC #: 

If CFC is unknown, use child's county/ZIP code, locate CFC office using the DHS Office Locator at: http://www.dhs.state.il.us/page.aspx?module=12

Section 6. Authorization to Release Information

1. Consent for Referral to Early Intervention and for Release of Health Information to Early Intervention Program

   The purpose of this disclosure is to refer (print child's name) to the Illinois Early Intervention program.

   I, (print name of parent or guardian), give my permission for my child's health care provider, (listed in Section 4 above) to share pertinent information about my child, (print child's name) regarding suspected developmental delay or related medical conditions with the Early Intervention program. I understand that I may withdraw this consent by written request to my child's health care provider, except to the extent it has already been acted upon.

2. Consent to Release Early Intervention Reports and Results to Healthcare Provider and/or Other Referring Agency.

   Your consent allows the Early Intervention program to share reports and results, as listed in the EI Fax Back Form, with your child's health care provider listed in Section 4, or the referral entity. The CFC will send the HFS 652 Illinois Early Intervention Program Referral Fax Back form with the appropriate information: https://www.illinois.gov/hfe/SiteCollectionDocuments/hfs652.pdf

3. Consent to Release Early Intervention Eligibility Determination and Service Information to Illinois Department of Healthcare and Family Services. For children enrolled in All Kids, your consent allows the release of information from Department of Human Services (DHS) to the Department of Healthcare and Family Services (HFS) about your child, including name, AllKids recipient identification number, date of birth, and information about your child's referral to and eligibility for Early Intervention, including services received and other referrals made by Early Intervention. Your consent allows HFS to share information with your child's health care provider (listed in Section 4 above, if any) and treating doctors within the group, and managed care organization (MCO), if applicable, for care coordination. Care coordination allows your child's health care provider to be notified with results of your child's Early Intervention evaluation and/or assessment, eligibility for services and services received. Your consent allows HFS to use the information for analysis purposes and to measure the quality of the care coordination process between the health care provider and Early Intervention. Information and reports resulting from data analysis will not be released with any individually identifying information about your child.

   I understand that I may withdraw this consent by written request to Early Intervention, except to the extent it already has been acted upon. I certify that this Authorization to Release Information has been given freely and voluntarily. Information collected hereunder may not be re-disclosed unless the person who consented to this disclosure specifically consents to such re-disclosure and or the re-disclosure is allowed by law. I understand I have a right to inspect and copy the information to be disclosed.

Parent/Legal Guardian Signature* __________________________ Date ________________

*Consent is effective for a period of 12 months from the date of your signature on this release.

Section 7. For CFC Office Use Only

Date Referral Received: __________________________ Name of person receiving referral: __________________________

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Illinois Early Intervention Program
Referral Fax Back Form

PART 1 of 2

Complete Part 1 upon contacting the family, or when a family cannot be contacted in a timely manner. If the parent/guardian consented to the release of information in Section 6 of the Standardized Illinois Early Intervention Referral Form to the health care provider listed in Section 4 and/or the referral source listed in Section 3, send Part 1 of the Referral Fax Back Form to the health care provider and/or the referral source for which consent was provided. If the parent/guardian did not consent to the release of information to either the healthcare provider or the referral source, then information cannot be sent to the entity for which consent was not given.

Date: ____________________________

Child's Name: ______________________ Date of Birth: ______________________

Parent/Guardian Name: ____________________________

Date Referral Received: ____________________________

This child was referred to our Child and Family Connections office. The following is the status of that referral:

☐ The family was contacted on (date): ____________________________

☐ A Service Coordinator has been assigned to the family:

Name: ____________________________

CFC# / Location: ____________________ / ____________________________

Phone Number: ______________________ Fax Number: ______________________

E-Mail: ____________________________

☐ Repeated attempts have been made to contact this family - we were unable to establish contact.

Date final contact attempt made: ____________________________

Please let us know if the family is still interested in having an evaluation for their child.

☐ The family has been contacted and requests that you contact them directly for results.

Date request made by family: ____________________________

☐ The family has declined services at this time.

Date service declined: ____________________________

Additional comments:

[Blank space for additional comments]
PART 2 of 2

To be completed after eligibility is determined and the Individual Family Service Plan (IFSP) is completed to inform the health care provider and/or referral source about Early Intervention eligibility, other referrals provided and other Early Intervention service(s) recommended, if eligible.

Note: if the parent/guardian consented to the release of information in Section 6 of the Standardized Illinois Early Intervention Referral Form to the health care provider listed in Section 4 and/or the referral source listed in Section 3, send Part 2 of the Referral Fax Back form to the health care provider and/or the referral source for which consent was provided. If the parent/guardian did not consent to the release of information to either the health care provider or the referral source, then information cannot be sent to the entity for which consent was not given.

Date:

Child's Name: __________________________ Date of Birth: __________________________

Parent/Guardian Name: __________________________

1. □ The family has been contacted and the following has occurred:
   □ The child has been evaluated and found to be not eligible for services at this time (Skip to #4)
   □ The child has been evaluated and found to be eligible for services based on the following:
     □ 30% or greater developmental delay
     □ Qualifying Diagnosis of:
     □ Other:

2. □ The child and family have been recommended to receive the following Early Intervention services:
   □ Developmental Therapy
   □ Occupational Therapy
   □ Physical Therapy
   □ Speech Therapy
   □ Social Work/Counseling
   □ Other:
   □ Notes:

3. □ An IFSP was/will be developed for the child and family. The IFSP Summary Report will be released to the health care provider identified in Section 6, Authorization to Release Information, in the Standardized Illinois Early Intervention Referral Form (a full copy of the plan may be obtained through the contact listed in Part 1).

4. □ The child and family received referrals to the following non-EI services:

5. □ The evaluation/assessment and service planning process have not been completed because:

Additional comments:

__________________________

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2 See “Identifying Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening” (http://pediatrics.aappublications.org/content/118/1/405.full).


4 For a model algorithm use the Quick Resource Guide or the link to the model here (https://www.cdc.gov/ncbddd/childdevelopment/screening-hcp.html).


7 The child health examination should include developmental and social and emotional screenings. Use of validated screening tools is recommended. Both screenings are billable, and space will be added to the Certificate of Child Health Examination form for documentation that the screenings were completed. It is important to note that finding developmental or emotional delays is not a diagnosis of mental illness. Implementation of PA 99-0927 is pending the promulgation of Administrative Rules.

8 Public Act 95-0469, Perinatal Mental Health Disorders Prevention and Treatment Act

9 https://www.healthcare.gov/preventive-care-children

10 Supra at note 8.


12 https://www.cdc.gov/ncbddd/childdevelopment/screening-hcp.html


14 For additional screening resources visit: https://www.acf.hhs.gov/sites/default/files/ecd/screening_compendium_march2014.pdf 15 To learn more about the Care Coordination Toolkit visit https://www.illinois.gov/hfs/SiteCollectionDocuments/NovemberCoordinatingMedicalHomes.pdf

16 For more info visit the EI Program website: http://www.dhs.state.il.us/page.aspx?item=31889

17 For more information about EI Service types/devices: http://www.ilga.gov/commission/jcar/admincode/089/089005000B00550R.html

18 For more information on screening for delay visit: http://www.aafp.org/afp/2011/0901/p544.html

19 For more information on medical diagnostics visit: https://blogs.illinois.edu/files/6039/114608/91776.pdf

20 For a list of eligible conditions visit: http://www.dhs.state.il.us/page.aspx?item=31244

21 For the legal definition of homelessness visit: https://nche.ed.gov/legis/mv-def.php

22 To access the EI referral form visit: https://illinois.edu/blog/files/6039/114611/4515.pdf

23 To visit UpstreamHealth: http://www.upstreamhealth.org


25 To access INCCRRRA visit this website: https://www.inccrrra.org/about/sdasearch

26 To access the SSI online application visit this website: https://www.ssa.gov/disability/disability.html