Advocating for Change:
Supporting our Children to be Self-Advocates

Jessica Kramer, PhD, OTR/L
Melissa Demir, MSW, LICSW
http://sites.bu.edu/projectteam/
Funding Acknowledgements

• Department of Education, NIDRR Grant #H133G120091 (PI- Kramer)
What is the “Environment Perspective?”

• Most teens think of the environment as recycling and being green.

• Project TEAM describes the environment as the people, places, and things around us.

• For example, it’s our community and the people within it as well as the rules.
What is the Game Plan?

- A problem-solving process
- Can be used for any activity goal
- Based on disability rights
  - A focus on environment barriers, not impairments
  - Includes disability rights laws that support requests for changes
- Four steps: Goal, Plan, Do, and Check
- Each step has a ‘self-talk’ question
How can these steps of the Game Plan support youth?
Goal
What activity would I like to do?

Motion: Shoulder shrug
Symbol: Bullseye with arrow
Plan Step 1
What parts of the environment help me or make it hard for me?
Plan Step 2
What strategy can I use to change the environment?

Motion: Pointing to head in thinking motion
Symbol: Thought bubble
Plan Step 3
Would using this strategy change the activity for other people?

Motion: Gesturing/pointing to others
Symbol: Other people
Do

Who do I talk to about making this change?

Motion: hand making talking motion
Symbol: Person talking with talk bubble

YELL Lab, Boston University  http://sites.bu.edu/yell/  kramerbulab@gmail.com

Not for distribution

YELL Lab, Boston University  http://sites.bu.edu/yell/  kramerbulab@gmail.com

Not for distribution
Check
Can I do this activity now?

Motion: make a check with finger
Symbol: Check
Today’s Objectives

Through our own practice, we can then adjust levels of support to teach our youth:

1) How to understand how Disabilities Rights Laws help youth with disabilities
2) How to identify who youth should talk to depending on the situation
3) How to develop a script to advocate for change
4) How to provide the ‘just right’ level of support to your son/daughter when learning these skills.
What laws protect youth and when?

The Americans with Disabilities Act (ADA)
— *The right to be included in society. The right to be included in your neighborhood and community.*

The Individuals with Disabilities Education Act (IDEA)
— *The right to be included at school.*

The Rehabilitation Act (Rehab Act- Section 504)
— *The right to be included in places and programs run by the government.*
Disability Rights Laws

These laws can help three classes or ‘types’ of people with disabilities:

Customers/Users

- ADA- patron of a restaurant or store
- Rehab Act- post office user, DMV, national park

Students:

- IDEA- students ages 3-21.
- Rehab Act Section 504- students in primary or secondary school
- ADA- College students

Employees:

- ADA- employee in an office
- Rehab Act- government employees
What kind of person am I?

Because different people can help depending on the situation!

• Student: someone who studies and learns in a classroom

• Employee: someone who works for money

• Customer/user: someone who buys things and uses services
Directing requests to appropriate people

Because different people can help depending on the situation!

Identify the person in charge because they have the power to facilitate change

<table>
<thead>
<tr>
<th>If I am a <strong>student</strong>...</th>
<th>If I am an <strong>employee</strong>...</th>
<th>If I am a <strong>customer/user</strong>...</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can talk to:</td>
<td>I can talk to:</td>
<td>I can talk to:</td>
</tr>
<tr>
<td>My classmates*</td>
<td>My co-workers*</td>
<td>Employees</td>
</tr>
<tr>
<td>My aide</td>
<td>My job coach</td>
<td>Manager/Supervisor</td>
</tr>
<tr>
<td>My teacher(s)</td>
<td>My boss/supervisor</td>
<td>Customer service</td>
</tr>
<tr>
<td>My guidance counselor</td>
<td>Human Resources</td>
<td>Better business bureau**</td>
</tr>
<tr>
<td>My inclusion facilitator</td>
<td>MA office on Discrimination**</td>
<td></td>
</tr>
<tr>
<td>My principal</td>
<td>ADA compliance officer**</td>
<td>ADA compliance officer**</td>
</tr>
<tr>
<td>Legal advocate**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Social implications are key to consider in relation to peers (e.g., classmates, co-workers)

**In some cases, a special person or agency may need to be contacted

YELL Lab, Boston University
http://sites.bu.edu/yell/
kramerbulab@gmail.com

Not for distribution
Asking for Change Script

• Scripting is a tool commonly used for youth with disabilities
  • Social contexts can be tricky to understand
  • Visual information can be easier to process
  • Practice is key

“A script is what actors and actresses use to remember their lines for plays and movies. They practice their lines so they know what to say.”

• This specific script helps youth break down:
  • What their goal is and who they should talk to
  • What’s making it hard for them to achieve their goal
  • What would help and why a certain strategy or accommodation could help
Asking for Change Script

Step 1 Say hello and introduce yourself

Step 2 Explain the activity you want to do (your goal)

Step 3 Describe the part of the environment that makes it hard for you to do the activity (the barrier)

Step 4 Describe the strategy you want to use to change the environment (The strategies are: plan ahead, change spaces, change the rules, ask someone for help, use technology or things, teach others about abilities and needs)
Asking for Change Script

Step 5: Explain why using this strategy will help you do the activity

Step 6: If the person says no or suggests a different idea that will make it hard for you...

- Ask to use a different strategy or ask if they can think of another way to help you change the environment
- Explain the disability rights law that gives you the right to ask for this change (ADA, IDEA, or Rehab Act)
- Ask if someone else can help you. Write down their name and contact information.

- Ask the person where, when, and how the change will be made
Asking for Change Script

Step 7 Talk with the person to decide what you will do next:

- Look for more information,
- Talk to someone else, or
- Start using the strategy.

Step 8 Thank the person for meeting with you
Helping Your Youth Use the Script

• Symbols
• Orienting questions
• Bring up examples from the past
• Act it out
Using the Right Level of Support

- Give the level of support you feel is best for your own son or daughter
- Ask questions first rather than giving answers
- We suggest being as least directive as possible
  - Increase support as appropriate
- Make a good impression
Parent Prompting Scale

Start off by framing what the discussion will be about and what you're trying to support your youth in doing by having this discussion.

Step I: Ask general questions based on the “Game Plan”
This gives youth the opportunity to process the situation as independently as possible.
“What's making it hard for you to do ___?”
“Who strategy could you use if ______ is making it hard?”

Step II: Ask specific questions, but hold off on giving any answers away
This will help your son/daughter consider a specific part of the environment, strategy, or consequence of strategy use.
“What about the ______?”
“How might your teammates feel if you made that change?”

Step III: Give a concrete choice [choice must be an appropriate action/decision].
After providing this support, help the youth execute the chosen option.
“If the noise is distracting, is it helping you or making it harder for you?”
“Would that help or make it harder for your classmates to get their work done?”
“You can either talk to the teacher about your disability and the kinds of support you need, or else ask the teacher for help.”
“You could talk to the ticket taker, or you could ask to speak with the manager which one would you like to try?”

Step IV: Give a directive, advise the youth how to respond, or demonstrate/model what to do.
Also provide the youth with the opportunity to practice your suggested response.
“If I were you, I would ask the store worker because she knows where everything is.”
“Watch how I am going to tell the front desk that I need an audio guide.”
Asking for Help at the Music Studio

Asking for Change Script

The Asking for Change script can help you to ask for the changes you need in your environment. You can write your script before you ask someone to make a change in your environment. Then you can practice. This will help you make a good impression.

There are eight steps in the Asking for Change script. Each step has a symbol to help you remember what to say. Fill out the steps of the Asking for Change script to practice before your meeting with a person who can help you to make a change in your environment.

Step 1 Say hello and introduce yourself

Hi my name is
Nice to meet you

Step 2 Explain the activity you want to do (your goal)

I would like to record music in a music studio
Asking for Help at the Music Studio

Step 3 Describe the part of the environment that makes it hard for you to do the activity (the barrier)

meet new people, and

Step 4 Describe the strategy you want to use to change the environment
(The strategies are: plan ahead, change spaces, change the rules, ask someone for help, use technology or things, teach others about abilities and needs)

I have been in a music studio for a little bit and I need help by asking for help and going technology.
Asking for Help at the Music Studio

**Step 5** Explain why using this strategy will help you do the activity

It's my first time recording before.

**Step 6** If the person says no or suggests a different idea that will make it hard for you...

- Ask to use a different strategy or ask if they can think of another way to help you change the environment
- Explain the disability rights law that gives you the right to ask for this change (ADA, IDEA, or Rehab Act)

**Step 6** If the person agrees to your request or suggests a different idea that will help you...

- Ask the person where, when, and how the change will be made
Asking for Help at the Music Studio

Step 7 Talk with the person to decide what you will do next:
- Look for more information,
- Talk to someone else, or
- Start using the strategy.

Step 8 Thank the person for meeting with you

Thanks for your time with me, and have a great weekend!
So what happened?

- Youth role-played his script with peer mentor and facilitator.

- On the day of his outing, he looked at his script, but then shared his ideas from memory when he spoke to the music studio employee.

- Was able to share his experience in music studios and ask for help navigating the recording technology.
Requesting a Change in Rules

**Advocating for Change Script**

Think of an activity that you want to do. Then think about a part of the environment that would make it hard for you to do this activity. When this happens, you may need to talk to someone in charge to make a change in your environment. Use this script to practice what to say when advocating for a change in your environment.

**Step 1** Say hello and introduce yourself

*Hi my name is*  
*What's your name?*

**Step 2** Explain the activity you want to do (your goal)

*I was wondering if I could bring my compound bow to use at your range.*

**Step 3** Describe the part of the environment that makes it hard for you to do the activity (the barrier)

*It might be in the rules that you can't use a compound bow.*
Requesting a Change in Rules

Step 4 Describe the strategy you want to use to change the environment
(The strategies are: plan ahead, change spaces, change the rules, ask someone for help, use technology or things, teach others about abilities and needs)
I was wondering if you can make an exception

Step 5 Explain why using this strategy will help you do the activity
The strings are too tight and can’t usually be adjusted, and my bow has a specific grip and extra padding and makes it easier to fire
Step 6: Listen to the person's response. Decide if the answer will help you or make it hard for you.

If the person says no or suggests a different idea that will make it hard for you:
- Ask to use a different strategy or ask if they can think of another way to help you change the environment.
- Ask if someone else can help you. Write down their name and contact information.
- Explain how a disability rights law may help you make a change in your environment (ADA, IDEA, or Rehab Act).
  - Compound bow is safe, they can be folded up into portable size.
  - Is there anyone else I could talk to about making this change?

If the person agrees to your request or suggests a different idea that will help you:
- Ask the person where, when, and how the change will be made.
  - When will the rule change?
  - How will you change the rules to allow me to use my compound bow?
Requesting a Change in Rules

Step 7: Talk with the person to decide what you will do next:
- Look for more information,
- Talk to someone else, or
- Start using the strategy.

When will you talk to (other person) about making this change?
Could you contact me on my cell phone when this change made?

Step 8: Thank the person for meeting with you
Thank you for considering making this change
Goodbye
So what happened?

• This youth ended up changing his mind and deciding that he wanted to try the archery bow provided to him.

• Once he had completed his outing, he spoke with staff and explained that he would prefer to bring his own bow during a follow up visit to the archery place.
Requesting a Change in Rules II

Asking for Change Script

The Asking for Change script can help you to ask for the changes you need in your environment. You can write your script before you ask someone to make a change in your environment. Then you can practice. This will help you make a good impression.

There are eight steps in the Asking for Change script. Each step has a symbol to help you remember what to say. Fill out the steps of the Asking for Change script to practice before your meeting with a person who can help you to make a change in your environment.

**Step 1** Say hello and introduce yourself

```
"Hello my name is
```

**Step 2** Explain the activity you want to do (your goal)

```
Join an anime club
```

Not for distribution
Step 3 Describe the part of the environment that makes it hard for you to do the activity (the barrier)

The rule is that I have to be a MIT student to join the MIT anime club.

Step 4 Describe the strategy you want to use to change the environment (The strategies are: plan ahead, change spaces, change the rules, ask someone for help, use technology or things, teach others about abilities and needs)

Change the rules

(Turn the page over for steps 5-8.)
Step 5 Explain why using this strategy will help you do the activity

I want this club to be open to anybody.

Listen to the person's response. Decide if the answer will help you or make it hard for you.

Step 6 If the person says no or suggests a different idea that will make it hard for you...

- Ask to use a different strategy or ask if they can think of another way to help you change the environment
- Explain the disability rights law that gives you the right to ask for this change (ADA, IDEA, or Rehab Act)
- Ask if someone else can help you. Write down their name and contact information

Step 6 If the person agrees to your request or suggests a different idea that will help you...

Ask the person where, when, and how the change will be made

Where does the anime club meet?

Step 7 Talk with the person to decide what you will do next:

- Look for more information,
- Talk to someone else, or
- Start using the strategy.
The club did not allow him to join because of their rules about needing to be a student.

He decided to invite a friend and his peer mentor to a comic shop where they had a “comic night” all together.

While at the comic store, he spoke with the employee to get her suggestions about other clubs.
Physical accessibility requests

**Step 3** Describe the part of the environment that makes it hard for you to do the activity (the barrier)

It’s hard for me to see the menu. It’s hard for me when the floor is bumpy, because I might trip and fall. It

**Step 4** Describe the strategy you want to use to change the environment (The strategies are: plan ahead, change spaces, change the rules, ask someone for help, use technology or things, teach others about abilities and needs)

ask for help → someone who came with me or someone at restaurant
explain abilities and needs → explain that bumpy floor might make me trip

(Turn the page over for steps 5-8.)
Third Base: Do

Who do I talk to about making this change?

<table>
<thead>
<tr>
<th>Who would you talk to about making this change?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

In this situation, are you a...

- Customer/User
- Employee
- Student

What disability law can help?

- ADA
- IDEA
- Rehab Act (Section 504)

Copy what you wrote in each box of the “Asking for Change” script here.

1. Hello, I’m ________________________________.
2. {} I was referred to you by ________________________________.
3. {} I would love to have a tour of the Bedford campus with my peer mentor and peer leader. I would need to meet you on a Friday afternoon before December 3rd.
4. {} Do you have a tour on a Friday before December 3rd?
5. {} Plan ahead - what I’m doing right now is to plan what’s happening.
6. {} An appropriate way to ask this person for help with the plan is to talk to the peer mentor.
7. {} Planning ahead will help me figure out how to make a good first impression on the Bedford campus. I don’t know how to contact someone, so I’ll ask for help through email. See the contact information and name is there someone?

kramerbulab@gmail.com

http://sites.bu.edu/yell/

Not for distribution
Your Own Script

• Before we discuss how to specifically support your son/daughter in creating their own script... it’s time for you to create **YOUR SCRIPT**!

• Think about a situation that your son or daughter is going through. Think about the parts of the environment making it hard for them, come up with a strategy, and anticipate what may happen!
Thoughts?

• What was it like for you to write the script? How about to act it out?
• What helped you decide who would be the best person to talk to?
• Do you foresee any issues in how the person may respond to you?
Would using a strategy change the activity for other people?

• Two main questions to ask
  – Would using the strategy HELP or make it HARDER for other people to do the activity?
  – Would using the strategy make the activity more fun, less fun, or no change?

• Many youth care about how others will respond to their requests
  – Some worry if people will become upset or jealous
  – Talk through what may happen
  – Also focus on disability rights
Discussion and Questions

Feel free to contact Jessica Kramer (kramerj@bu.edu) or Melissa Demir (mdemir1@bu.edu) to talk more about Project TEAM and supporting youth in advocating for change!

http://sites.bu.edu/yell/

http://sites.bu.edu/projectteam/