



Youth and Young Adults Empowerment,
Leadership & Learning Lab: YELL

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

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



YELL Lab, Boston University

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

krambulab@gmail.com

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

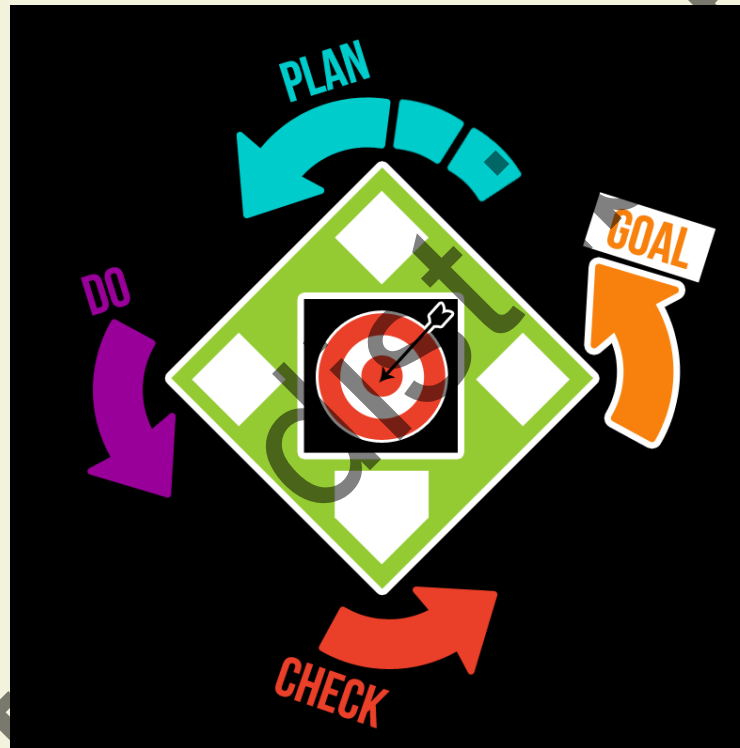




*How can these steps of the
Game Plan support youth?*

Goal

What activity would I like to do?

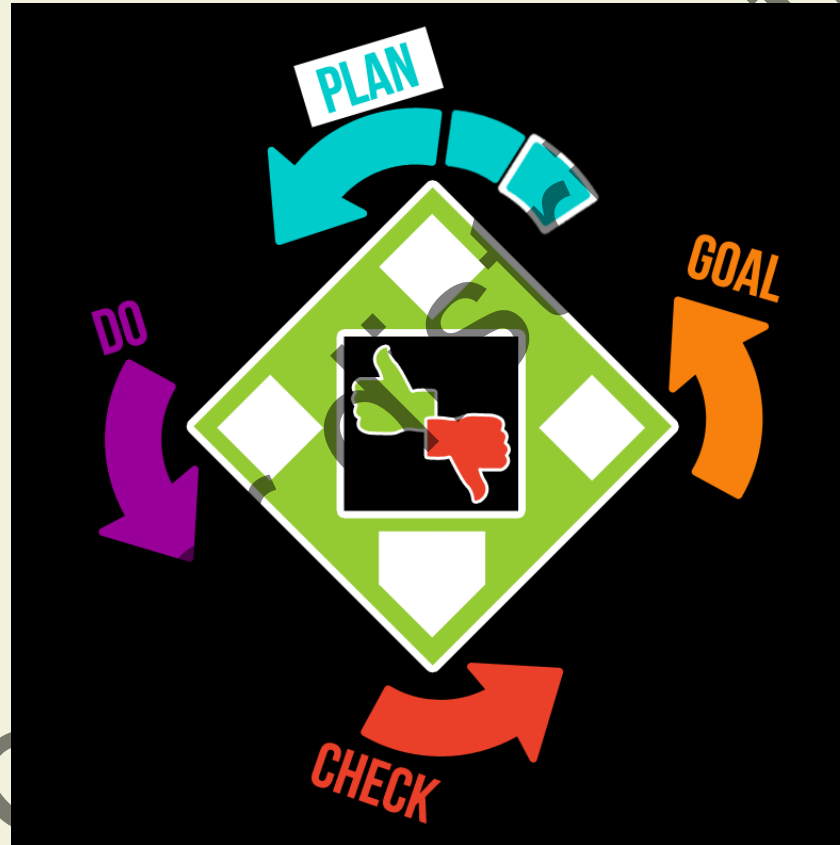


Motion: Shoulder shrug

Symbol: Bullseye with arrow

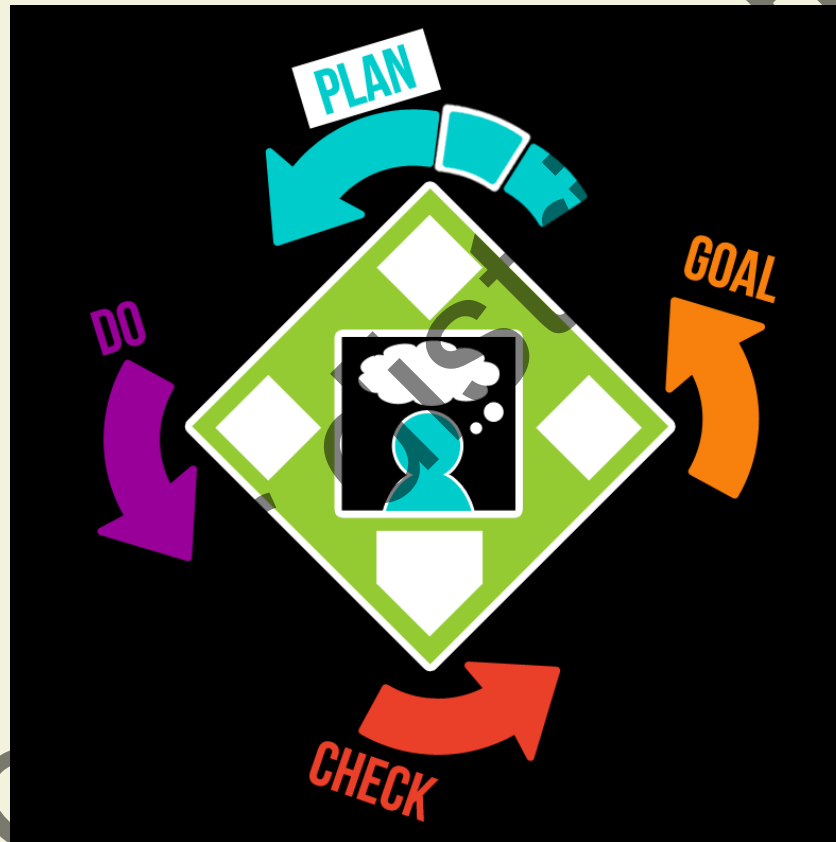
Plan Step 1

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?

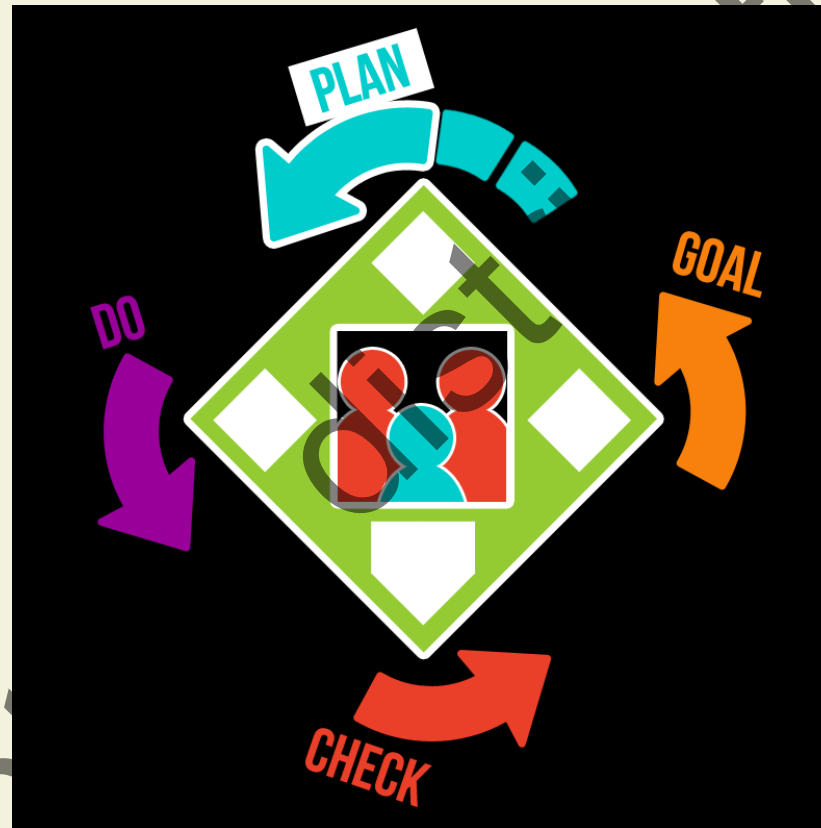


Motion: Pointing to head in thinking motion

Symbol: Thought bubble

Plan Step 3

Would using this strategy change the activity for other people?

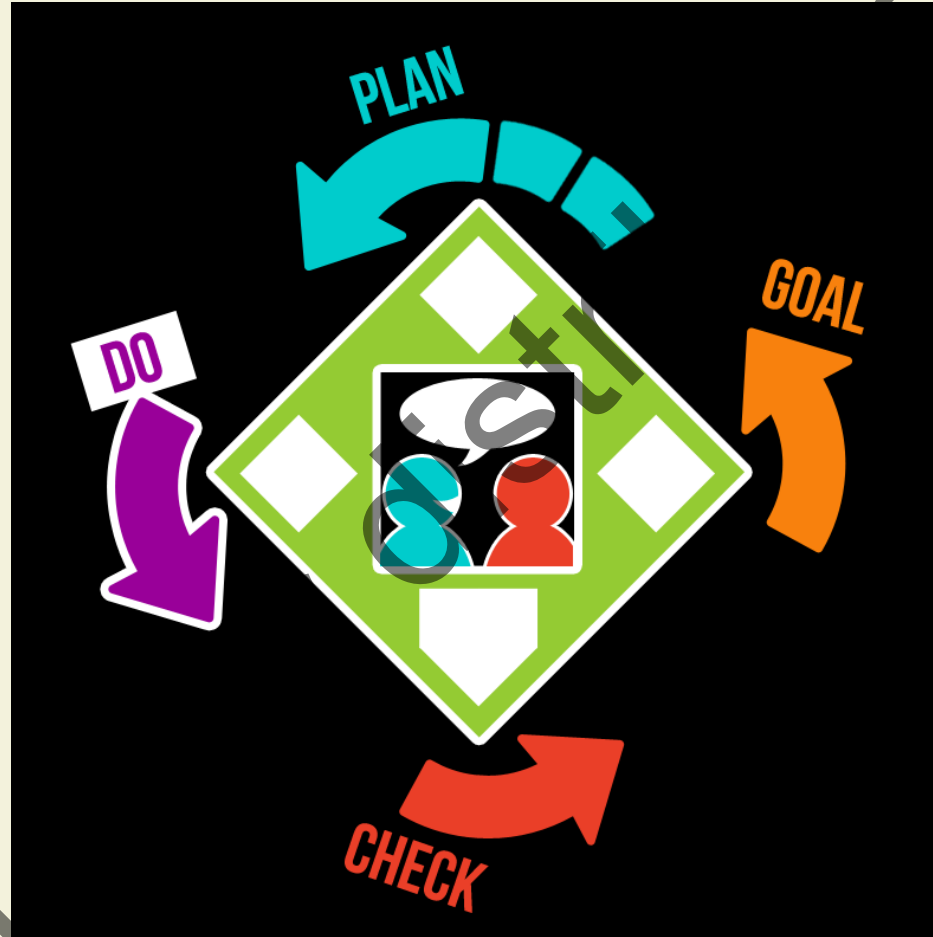


Motion: Gesturing/pointing to others

Symbol: Other people

Do

Who do I talk to about making this change?

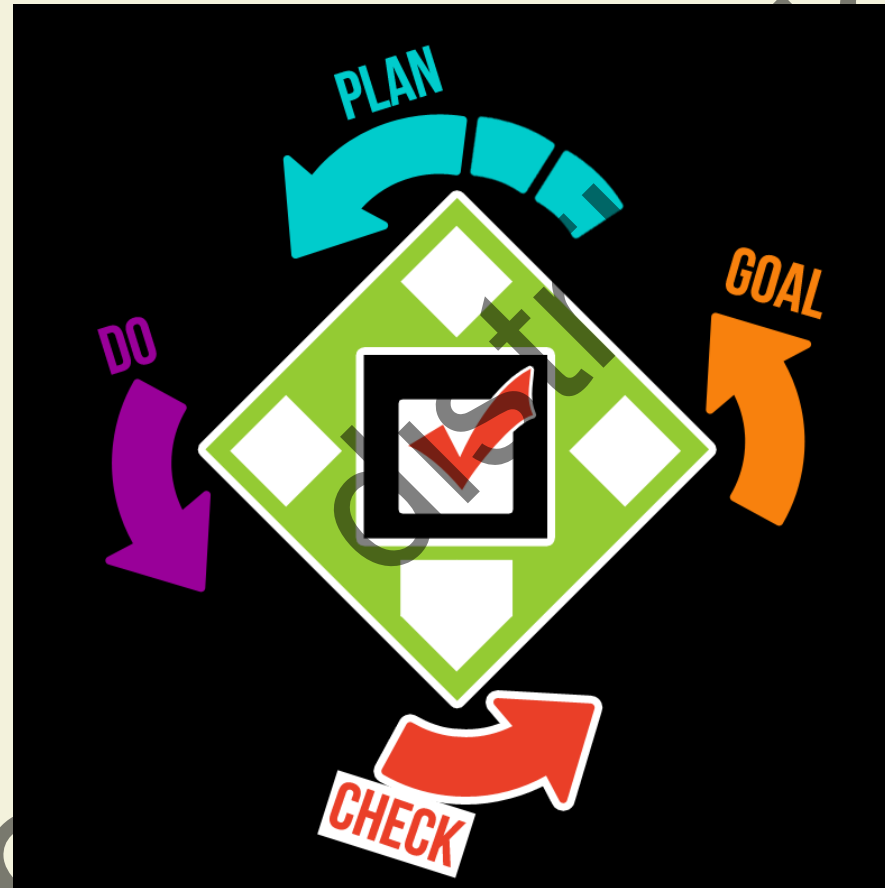


Motion: hand making talking motion

Symbol: Person talking with talk bubble

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

If I am a **student**...

I can talk to:

My classmates*
My aide
My teacher(s)
My guidance counselor
My inclusion facilitator
My principal
Legal advocate**

If I am an **employee**...

I can talk to:

My co-workers*
My job coach
My boss/supervisor
Human Resources
MA office on
Discrimination**
ADA compliance officer**

If I am a **customer/user**...

I can talk to:

Employees
Manager/Supervisor
Customer service
Better business bureau**
ADA compliance officer**

*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

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.



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 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 + into new people, and
~~recording the music~~ mark

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
using technology.

Asking for Help at the Music Studio

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



This is my first time recording
in a music studio before.

asking for help is
showing me what I need

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)



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 strings can be adjusted and my bow has a specific grip and extra padding and makes it easier to fire

Requesting a Change in Rules

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.

Requesting a Change in Rules II

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.)

Requesting a Change in Rules II

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

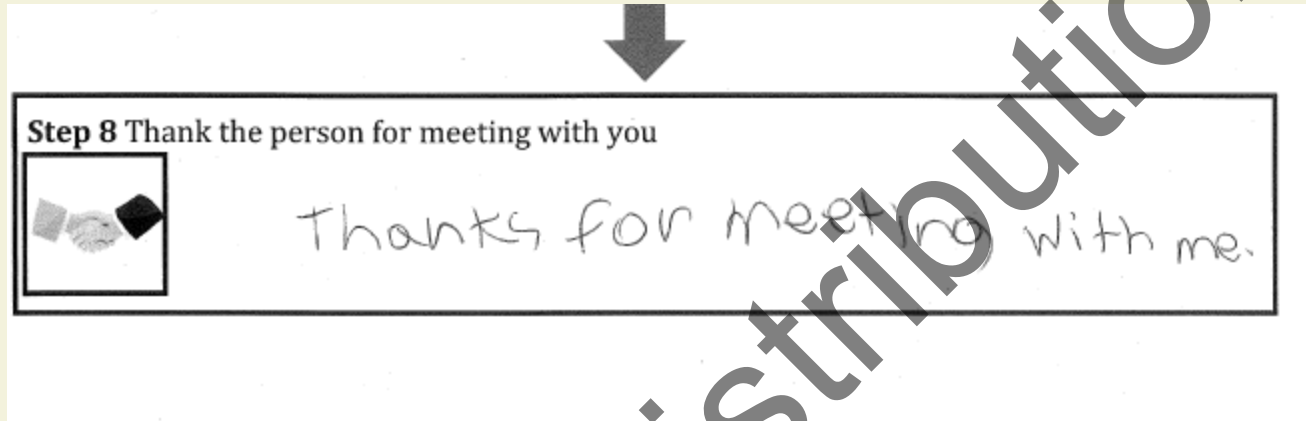
Where does the anime club meet?

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.

Requesting a Change in Rules II



- 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)

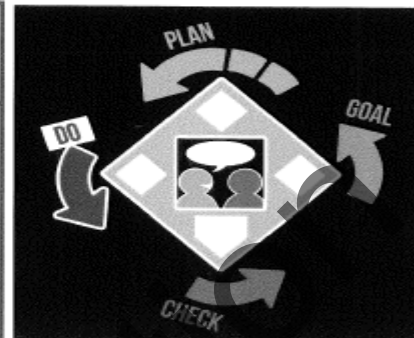


ask for help → Someone who came with ~~you~~ me or someone at restaurant
explain abilities and needs → explain that bumpy floor might make ~~for~~ me trip

(Turn the page over for steps 5-8.)

Third Base: Do

Who do I talk to about making this change?



Who would you talk to about making this change?

Name

SHUTCH, MARY, Title/Position

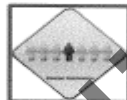
CAMPUS RECRUITER ↔ UNKNOWN NAME, TO BE DETERMINED

In this situation, are you a...

- ☐ Customer/User
☒ Employee
☐ Student

What disability law can help?

☐ ADA



☒ IDEA



☐ Rehab Act
(Section 504)



ON BACK!

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

1. Hello, I'm I WAS REFERRED TO YOU
2. BY BECAUSE I WANTED TO GO TO THE BEDFORD CAMPUS.
3. I WOULD LOVE TO HAVE A TOUR OF THE BEDFORD CAMPUS WITH MY
4. PEER MONITOR AND PEER LEADER. I WOULD NEED TO MEET
5. YOU ON A FRIDAY AFTERNOON, BEFORE DECEMBER 3RD
6. DO YOU HAVE A TOUR ON A FRIDAY BEFORE DECEMBER 3RD?
7. PLAN AHEAD-WHAT I'M DOING RIGHT NOW TO LEARN WHAT IS
8. AN APPROPRIATE WAY TO ASK THIS PERSON FOR HELP/
TALK TO SHE/HE. PLANNING AHEAD WILL HELP ME
FIGURE OUT HOW TO MAKE A GOOD FIRST IMPRESSION

ON THE BEDFORD CAMPUS RECRUITER. ASK IF SOMEONE CAN
 TO HELP ME GET THEIR CONTACT INFORMATION AND NAME. IS THERE SOMEONE
 IN THE OFFICE OF EQUAL OPPORTUNITY WHO CAN RUN THE TOUR INSTEAD?

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



Youth and Young Adults Empowerment,
Leadership & Learning Lab: YELL

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/>