Chronic Disease Self-Management Program in American Sign Language: Evaluation Summary and Recommendations

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I. Introduction

The Chronic Disease Self-Management Program (CDSMP) is a six-week workshop offered in community settings for people with chronic conditions to learn how to manage their diseases. CDSMP is an evidence-based program that is effective in managing chronic conditions and improving health outcomes in a variety of populations; [1-18] however, the workshop may not effectively reach the deaf or hearing impaired community. An estimated 4.8 million Americans cannot hear well enough to understand speech and American Sign Language (ASL) is the third most commonly used language in the United States.[19] People who are hard of hearing or deaf have poor health outcomes and low health literacy.[20]

II. Methods

As far as we know, CDSMP has never been offered in ASL. In March-April 2016, the Ohio Disability and Health Program (ODHP) worked with the Deaf community in Columbus, Ohio to coordinate a pilot of the Chronic Disease Self-Management Program developed by Stanford University in American Sign Language (ASL).

First, volunteers fluent in ASL were recruited and participated in the 4-day CDSMP lay-leader training with sign language interpretation. Second, the lay leaders worked with Jane Acri, the Central Ohio Area Agency on Aging's CDSMP Coordinator, to identify aspects of the CDSMP workshop that may require adaptation such as the manner in which material is presented or accessibility of the content for the Deaf community. One concern was raised about the hand-written charts and diagrams used to illustrate concepts during the workshop, because lay leaders use their hands to communicate in ASL. The concern was raised about being unable to write and speak at the same time and that turning away from participants to scribe brainstorming activities would be disruptive. We adapted the CDSMP curriculum to use printed workshop charts with

visuals in place of handwritten charts (see Appendix C). Other minor issues were also raised including the practice of having participants close their eyes and listen to instructions for the body scan and meditation exercises.

Third, volunteers led a 6-week CDSMP workshop in ASL and ODHP staff collected fidelity evaluation data based on Stanford's *Fidelity Check List* at each of the six workshop sessions. Finally, workshop participants completed weekly questionnaires to assess satisfaction with the program and participated in a focus group following workshop completion. Additionally, we conducted structured interviews with lay leaders following the workshop to get their feedback.

This report shares the findings of this pilot study, including data on program fidelity, participant satisfaction, and qualitative feedback from participants and lay leaders on what adaptations worked best and suggestions for additional adaptations that may improve the program's accessibility and applicability to the Deaf community. Recommendations are made on how to best implement CDSMP in ASL based on these data.

Participants

Eight participants were recruited for this pilot workshop, including seven females and one male, three between the ages of 35-54, four between the ages of 55-64, and one age 65 or older (see Table 1 for participant demographics). Chronic conditions reported by participants included: Autoimmune (FMS), neuropathy, chronic pain, fatigue; thyroid autoimmune disease; thyroid; high cholesterol, sleep apnea; high blood pressure, back and leg pain; neck and arm pain; arthritis, and family stress. Two participants attended six of the six sessions, four participants attended five of the six sessions, and two participants attended two of the six sessions.

Table 1. Participant Demographics

Gender	Male	12.5% (n = 1)
	Female	87.5% (n =7)
Age	18-21	0% (n= 0)
	22-24	0% (n = 0)
	35-54	37.5% (n = 3)
	55-64	50% (n = 4)
	65 or older	12.5% (n =1)
Hispanic/Latino	Yes	0% (n = 0)
	No	100% (n = 8)
Race	American Indian/Alaskan Native	0% (n = 0)
	Asian	0% (n = 0)
	Black or African American	0% (n = 0)
	White	100% (n = 8)
	Other	0% (n = 0)

III. Results

Program Fidelity

Program fidelity was assessed using a fidelity check list developed by Stanford University. Time was recorded in seconds for each session activity. Additionally, it was noted whether each session was 2.5 hours long, if there were two lay leaders present to teach the workshop, if leaders arrived on time, if leaders did not leave early, if leaders used facilitation techniques appropriately and effectively, if a weekly attendance record was kept, and if leaders followed the curriculum and limited the program content to information and activities as described in the English Leaders Manual with proposed adaptations and translation into ASL. Table 2 demonstrates the summary of the fidelity questions for each session. Fidelity measures were met for all sessions with a few exceptions. One session went over on time by 34 minutes. The average length of sessions was 8974 seconds or 2.49 hours, with the shortest session being 8519 seconds (2.37 hours) and the

longest being 10,220 seconds (2.84 hours). Table 3 shows the breakdown of the average time of each activity and breaks in each of the six sessions.

One of the lay leaders was impacted by a chronic condition during the pilot workshop and was unable to attend three of the six sessions. So as not to skip weeks and based on availability of substitutes: One session (session 4) was facilitated by Jane Acri, Master Trainer, (ASL interpreter provided, one session (session 5) was facilitated by only one leader fluent in ASL, and one session (session 6) was facilitated by Jane Acri (with an ASL interpreter) and one leader fluent in ASL

Table 2. Summary of Observation Checklist

Item	**Session 1**	**Session 2**	**Session 3**	**Session 4**	**Session 5**	**Session 6**
1. Session is 2.5 hours	Yes	Yes	Yes	No	Yes	Yes
2. Two Leaders present to teach the workshop	Yes	Yes	Yes	No	No	Yes
3. Leaders arrive on time	Yes	Yes	Yes	Yes	Yes	Yes
4. Leaders do not leave early	Yes	Yes	Yes	Yes	Yes	Yes
5. Leaders use facilitation techniques appropriately and effectively	Yes	Yes	Yes	Yes	Yes	Yes
6. Weekly attendance record is kept	Yes	Yes	Yes	Yes	Yes	Yes
7. Leaders follow the curriculum and limit the program content to information and activities as described in the Leaders Manual with proposed adaptations and translation into ASL	Yes	Yes	Yes	Yes	Yes	Yes

Table 3. Average Time of Activities in Seconds

Session #	Average time per Activity (seconds)										Time (seconds)
	A1	A2	A3	A4	A5	A6	A7	A8	Break 1	Break 2	
1	1,200	1,320	1,880	600	1,750	720	0	0	1,170	300	8,940
2	1,532.5	2,471	1,782.5	739	684.5	270	0	0	1,110	0	8,589.5
3	1,260	1,380	1,900	600	1,760	471	0	0	1,360	0	8,731
4	1,043	1,365	2,485	1,972	1,495	900	0	0	0	960	10,220
5	900	1,980	1,255	600	930	870	600	300	0	1,410	8,845
6	1,388.5	1,911.5	1,925.5	1,643.5	600	0	0	0	0	1,050	8,519

Participant Satisfaction

Participant satisfaction was assessed through the use of weekly questionnaires. Figure 1 shows the percentage of participants who chose each response option (strongly agree to strongly disagree) for each of the seven questions averaged over the six sessions. On average over the six weeks, the majority of respondents “agreed” (69%-82%) or “strongly agreed” (9%-23%) with each satisfaction question, demonstrating a high level of overall participant satisfaction with the pilot workshop.

Question 1: This session presented skills and concepts that were new to me

Question 2: This session was well organized

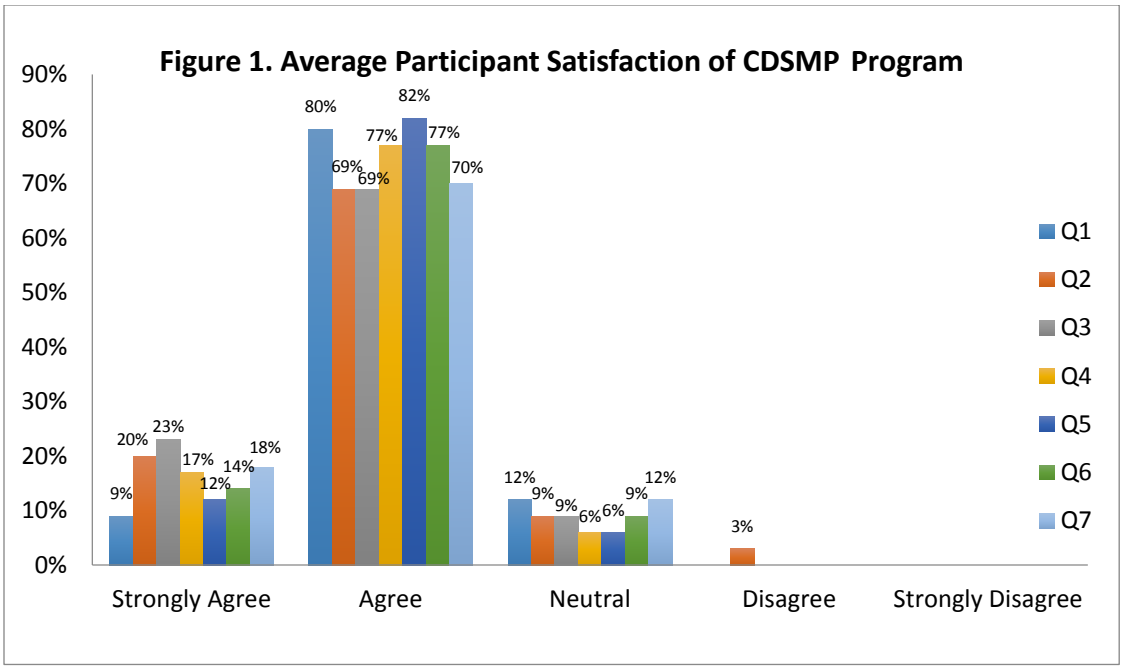
Question 3: The leaders were effective in explaining concepts to me

Question 4: The teaching methods helped me understand concepts more clearly

Question 5: Concepts presented during this session were clear to me

Question 6: I feel confident to apply concepts I learned today in my everyday life

Question 7: Overall, I felt this session was useful to help me manage my chronic disease



Focus Group/Interview Feedback

Following completion of the six workshop sessions, a focus group was held with six workshop participants and structured interviews were conducted individually with each lay leader (see Appendix A for specific focus group questions). The focus group and interviews were conducted by an ODHP staff member and a graduate research assistant through a certified ASL interpreter. Audio was recorded and transcribed for the participant focus group and for one of the lay leader interviews (recording device malfunctioned during the second lay leader interview but detailed notes were taken). ODHP staff and a graduate research assistant worked together to review focus group/interview materials and identify salient feedback and themes (see Appendix B for focus group feedback).

Overall, feedback from participants and lay leaders was positive. Lay leaders and participants discussed how much they appreciated participating in the workshop. The importance

of having the workshop offered in ASL directly by a fluent lay leader was also highly stressed by participants and lay leaders. Participants reported that it was very difficult to form a bond with the facilitator during the one session when an ASL interpreter was used. Offering the workshop in ASL allowed participants to understand the material and communicate with their peers in a way that is much more effective and comfortable than participating in a workshop among participants who do not use ASL.

Both participants and lay leaders were positive about the adapted session charts created for this pilot as far as content and images. However, all groups reported that there were too many charts up at one time during workshop sessions and that this was distracting. Suggestions included having only one chart up at a time, using a projector to display the chart that is currently being used, or giving participants handouts of all session charts. Lay leaders also discussed certain concepts and activities they felt were difficult for participants, including tying together concepts from the toolbox and the decision-making activity. They suggested that more concrete examples could help to convey these concepts. One lay leader commented that brainstorming activities may take longer with Deaf participants due to the importance of story-telling in the Deaf community. Participants and lay leaders reported that many health topics were covered in each session and that the pace of the workshop was fast. However, the duration of activities was generally consistent with the length of activities in a typical workshop. It is unclear whether this feedback was typical of CDSMP participants or if this was Deaf-specific. Some participants suggested including more frequent breaks to allow participants to rest their eyes and absorb the material.

IV. Recommendations when offering CDSMP to the Deaf community

Based on participant satisfaction and the high degree of fidelity to the standardized CDSMP curriculum, we conclude that CDSMP can be successfully offered in ASL to Deaf participants with minimal adaptations. Furthermore, based on the feedback concerning how important it is for Deaf individuals to access health information and public health programming in ASL, we strongly encourage others to implement this program in ASL. The following recommendations are offered to guide future CDSMP in ASL workshops:

1. Recruit lay leaders from the Deaf community who are fluent in ASL and can offer the program directly in ASL to participants without the use of an interpreter.
2. Consider collaborating with a center that provides services to the Deaf community to facilitate workshops. Consider partnering with Deaf specific churches, schools, community centers, senior centers, or assisted living facilities, interpretation service providers or other Deaf specific service providers. Creating a partnership with an organization that employs individuals who are fluent in ASL and that would support their employees' time in facilitating CDSMP in ASL as a lay leader would be ideal.
3. Particular consideration is needed as to the physical location of the workshop. Ensure that the location meets ADA accessibility requirements and that the room is well-lit in all areas. Adequate lighting is very important for effective communication in ASL.
4. Lay leaders should expect to take extra time to review the lay leader manual and think about how they will translate the text during workshop sessions. Lay leaders should familiarize themselves with health-related ASL terms prior to beginning the workshop.

5. Lay leaders should make adaptations to the language used in the lay leader manual that are not relevant to the Deaf community. For example, change “the mind is like a radio” to “the mind is like a television.”

6. Only display one chart at a time during the workshop so that participants are not distracted.

7. Arrange for appropriate accommodations for handwritten charts in sessions. Lay leaders using ASL to communicate will be unable to write. Lay leaders may choose one or a combination of the following suggestions:

    - Use charts with visual images instead of relying on handwritten materials. A set of charts was developed for this pilot that could be used or modified (see Appendix C).
    - Provide participants with a packet of the charts to be used during workshop sessions, either in an electronic format and/or as a printed handout. This will allow participants to take notes during sessions and review materials presented in session at home.
    - If lay leaders have access to a computer and projector, consider using it to display charts and to type out participant comments/brainstorming ideas. This will allow the lay leaders to continue to face the participants as they record participant comments and will reduce the number of participant comments missed by the lay leader due to not being able to see what the participants are signing. The use of this technology deviates from Healthy U’s low-tech approach but may be considered to be a reasonable accommodation for the Deaf community.

8. Replace the guided body scans/meditation sessions where participants are asked to close their eyes with other exercises. Additional breathing exercises, such as the yogic "Three-Part Breath" or others, could be used in place of their exercises. Do not use relaxation exercises which require participants to close their eyes at any time.
9. Allow for more frequent, shorter breaks during each session to allow participants time to rest their eyes and refocus. It may be beneficial to extend the time for each session by as much as a half hour to allow additional time for these breaks. This could be determined on a workshop by workshop basis depending on group consensus and could be discussed in the "Session 0" introduction.
10. Include Deaf-specific content in Session 6 where communication with healthcare providers is discussed. Content could include issues with ASL interpretation in a medical setting (issues with medical terminology/translation errors, billing complications, rights regarding interpretation, etc.), making requests for accommodations, use of the video relay service with healthcare providers, and advocating for one's self as needed in a healthcare setting among other potential topics. A brainstorm specific to Deaf issues around communicating with healthcare providers could be added to this session to ensure that participants feel their unique needs are addressed. The following topics may be addressed in Session 6:
    - Problems with healthcare process
        - Staff call my name instead of coming to try to find me in waiting room
        - Health care providers refuse to provide an interpreter
        - Quality of interpreters variable

- Staff will talk to interpreter privately and I don’t know what they are saying
- Difficulty understanding medical terminology
- When cancelling appointment, doctor needs to also cancel interpreter
- Office leaves message so fast that you can’t understand it
- Billing system charges how much time you spend with doctor and it takes longer with an interpreter
- Providers struggle with video relay service to place and receive telephone calls from Deaf patients

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Appendix A: Focus Group Questions

Healthy U in ASL Focus Group Guide

I. Opening Questions

a. What did you think of the Healthy U program?
b. What did you like about the Healthy U program?
c. What did you not like about the Healthy U program?

II. Follow Up Questions

a. What needs improvement in the Healthy U program?
b. What do you think about the teaching methods used during the Healthy U program?
c. Suppose you were in charge, what is the one most important thing you would change about how the workshop is taught?
d. What helped you learn the material?
e. What got in the way of you learning the material?
f. What is the topic from the Healthy U program that was most clear to you?
g. What is the topic that was the most unclear to you?
h. How could that topic have been made more clear?
i. What do you think of the use of visual aids during the sessions?
j. What do you think of the use of PowerPoint presentations during the sessions?
k. What do you think of the use of posters during the sessions?
l. What do you think of the use of flipcharts during the sessions?
m. What do you think of the use of the book during the sessions?
n. What activities do you think were the most useful during the Healthy U program?
o. What activities do you think were the least useful during the Healthy U program?

III. Final Questions and Wrap Up

a. Of all things discussed today, what to you is the most important?
b. Moderator review purpose of study and ask: Have we missed anything that you want to comment on?
c. Thank you for your participation!

Appendix B: Participant and Lay Leader Feedback

The following list summarizes the main feedback points relayed by each lay leader (LL) and by participants during focus groups/structured interviews. Feedback is divided into three categories: 1. positive comments regarding the pilot workshop; 2. negative comments regarding the pilot workshop; and 3. suggestions for additional adaptations or improvements to the workshop in ASL. It is important to note that not all comments, either positive or negative, or suggestions were specific to offering CDSMP in ASL. Some comments are more general and are not disability specific.

Lay Leader Positives:

- Participants benefited from/liked weekly action planning process.
- Participants benefited from/liked nutrition section of workshop.
- Overall, very positive about workshop for the Deaf population.
- Participants liked meditation adaptations.
- Participants understood the importance of meditation.
- Peer support/peer suggestions/problem solving were valuable and worked well
- Content/images in charts were good.

Participant Positives:

- Overall, very positive feedback about the program and their participation in it.
- Workshop gave me great information and a great starting point to begin discussing health matters with healthcare providers.
- Learned a lot about health/managing chronic conditions.
- Great opportunity for Deaf people to access workshop.
- Great to know that we can be a part of our own health process.
- It is usually hard to be the only Deaf person in the room and still grasp the material being presented because it is so hard to keep up – Participation/learning is much more effective in a Deaf only group facilitated in ASL.
- Liked brainstorming activity.
- Action planning helped me stay motivated.
- I found distraction techniques helpful.

Lay Leader Negatives:

- Deaf participants unable to look at visuals and hear LL (lay leader) at the same time (charts were distracting).
- Liked chart content but needed a better way to utilize.
- Symptom cycle was difficult to explain.
- Manual references to hearing, such as "the mind is like a radio…" are not relevant to this population.
- Some toolbox concepts were confusing for participants; tying them all together was challenging.
- Translating the material into ASL is time consuming and exhausting; a background in medical translating would be helpful for LL to have.
- Difficult to translate in real-time; required pre-session preparation as does the workshop in English
- Charts were too distracting – too many were up at one time and participants did not know where to look.
- Exercise section was not useful; participants were not well-engaged in this material.
- Some participants struggled with understanding prioritization and the decision-making activity.
- Going off topic during sessions slowed the pace of the workshop (not related to disability status). Participants sometimes got caught up exchanging stories and were difficult to redirect to topic at hand.

Participant Negatives:

- Pace was too fast.
- Participants were asked to look at too many things at once, not enough examples given.
- Too many concepts covered per night.
- More time is needed to understand health concepts.
- Charts were confusing; too many words, not enough pictures, too many up at once.
- The toolbox Chart was presented in three sections – this was too big.
- Eyes got tired taking in so much visual information with infrequent breaks.
- Relaxation techniques were difficult to do without auditory guidance; difficult to "get into" it.
- Closing eyes cuts off our channel of communication and is stressful.
- Lay leaders could have been more prepared.
- Not enough details on food topics.

Lay Leader Suggestions:

- Provide participants with print outs of the charts.
- Allow more time for activities, such as brainstorming. This activity may take longer due to Deaf culture/storytelling.
- Too many activities to cover in 6 weeks; either cut out material or have more sessions.
- Do not have Deaf participants close their eyes at any point.
- Provide another example of decision-making.
- Have no more than 6 people per workshop.
- LL must know ASL in order for a bond to form between LL and participants (stressed as highly important).
- PowerPoints may be less distracting than printed/hand written charts.
- Give LL ability to type out charts/brainstorm feedback, etc. on a keyboard and have this show up on a projected screen.
- In so far as possible, present things visually.

Participant Suggestions:

- Hold sessions in well-lit locations (shadows made it difficult to read ASL).
- LL must come from the Deaf community and be fluent in ASL (stressed as highly important).
- Have shorter but more frequent breaks to allow rest time for our eyes.
- Provide participants with either an electronic version of all charts or a printed booklet with all charts, so that we can make notes and take this home to review later.
- Only have one chart up at a time or use a projector/PowerPoint to display one chart at a time.
- Provide Deaf-specific information on communicating effectively with healthcare providers.
- Don't encourage letter-writing to healthcare providers (many Deaf individuals do not have strong English grammar skills).
- Provide more time for Q&A after sessions/activities.
- Provide more time for participants to learn and process the body scan exercise.
- Extend workshop by 2-3 weeks so that fewer topics can be covered each session.
- Briefly review material from previous session at beginning of each session.
- Reduce the number of concepts covered per session.
- Provide more concrete examples for each concept.

- Provide a real-life demonstration on food portioning.
- Have a pre/post-test either for each session or for the workshop as a whole so that participants and LL can ensure that material is being conveyed.
- Before the workshop begins, go over workshop expectations, the book/homework assignments that will come up, the action-planning/problem-solving processed we will be expected to engage in.

Appendix C: Modified Charts

Self-Management Tasks

Take Care of Health Condition

(Talking to your doctor, taking your medication, exercising, changing eating habits)

Carry out Normal Activities

(Chores, employment, social life)

Manage Emotional Changes

(Coping with life changes and difficulties)

Self-Management Tool Box

Physical Activity

Decision Making

Breathing Techniques

Understanding Emotions

Self-Management Tool Box

Medications

Action Planning

Working with Health Professionals

Problem-Solving

Self-Management Tool Box

Healthy Eating

Communication

Sleep

Weight Management

Steps to Creating an Action Plan

1. Pick something YOU want to do!

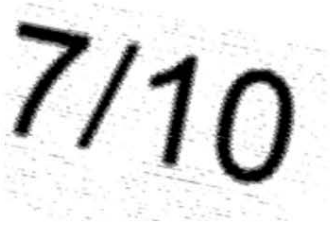
2. Make your goal achievable

3. Ask what?

4. Ask how much?

5. Ask when?

6. Ask how often?



7. Rate confidence level

Problem-Solving Steps

1. Identify Problem

2. List Ideas

3. Select an Idea

4. Assess the Results

5. Try Another Idea

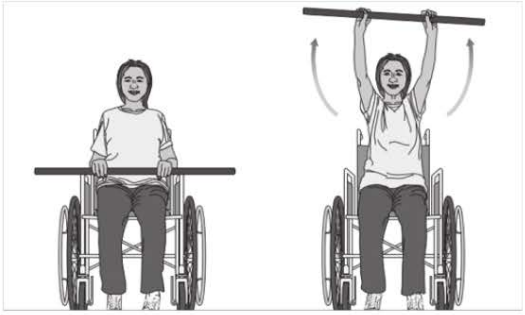
6. Use Other Resources

7. Accept that Problem may not be Solvable Now

Three Kinds of Physical Activities and Goals

Flexibility

Goal: 10 minutes without stopping



Strengthening

Goal: 8-10 strengthening exercises 2-3 days per week

Aerobic

Goal: Moderate aerobic exercises 30-40 minutes, 3-5 days per week

Reduce the Risk of Falling

Exercise

Have vision checked

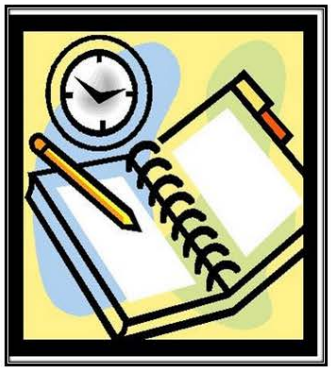
Take care of your feet

Make your home safer

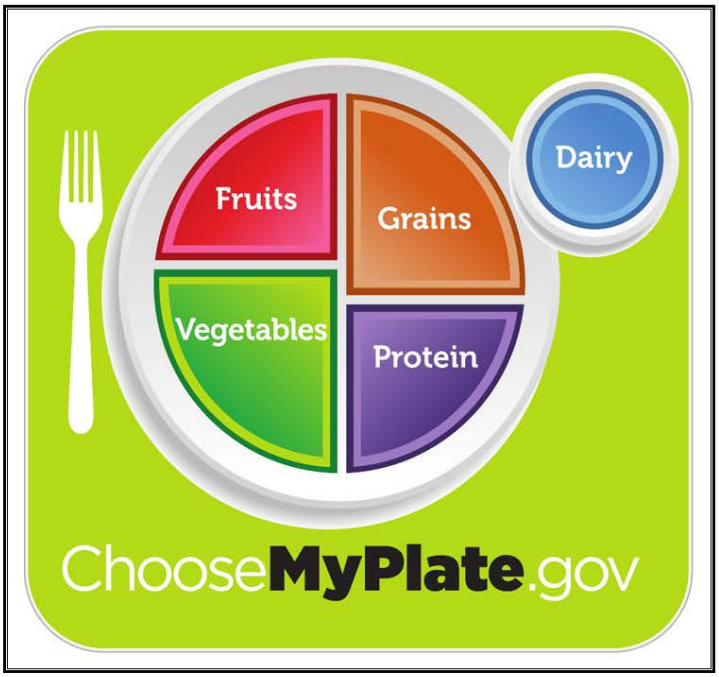
Talk to your healthcare provider

Healthy Eating Means…

- Eating Breakfast
- Eating a Variety of Foods
- Eating Meals and Snacks Regularly
- Watching portion sizes



The Plate Method



Healthy Eating Guidelines

Seven Servings of Fruit and/or Veggies Per Day

Choose Foods Lower in Fat

Limit Foods that Raise Cholesterol

Watch Carbohydrates

Reduce Salt or Sodium

Maintain a Healthy Weight