



Self-Determination and Child-Centeredness

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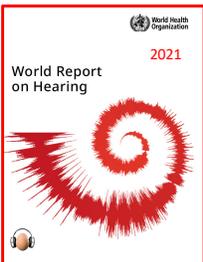
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Learning Outcomes

1. Name one concern regarding young persons with HI re: college and employment.
2. List three subskills related to the development of self-determination.
3. Describe relationship between self-determination and post-high school outcomes.

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Starting Point:



- 2019: Reviewer, background papers re: young people w/HI
- Measurable outcomes: concerns



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Higher Education/Career Training

- Post-secondary enrolment rates: overall, comparable to same-age peers
 - Comparable entrance qualifications (grades, exam scores, letters of rec, etc.)
- Degree-completion rates: **1/3 lower** compared to same age-peers
- Contributing factors include lack of preparation:
 - Assuming responsibility to request assistance and technologies
 - Exercising self-advocacy skills
 - Developing social support systems

(Boutin, 2008; Fuller et al, 2004; Katsiyannis et al., 2009; Mamiseishvili & Koch, 2012; Sanford et al., 2011)

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Also: Employment Status

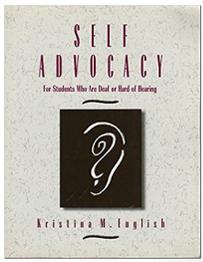
- Overall, rates of employment comparable to same-age peers in general population
- On average, salaries are lower
 - Likely related to lower degree completion rates, subsequent employment in less skilled jobs
- Reported barriers include inherent difficulties with work situations
 - Meetings, supervision, training, social functions
 - Reluctance to advocate for oneself by disclosing hearing problems, requesting accommodations

(Hogan et al., 2009; Mohr et al, 2000; Punch et al., 2007; Sanford et al., 2011)

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Different Approaches: Help Child Grow In...

- Self-Advocacy
 - Knowledge (legal rights, K-12 and post-secondary)
 - Skills (Interpersonal communication: explaining rights, accommodations to others, etc.)



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Also...

- Self-Regulation / Self-Awareness
 - Healthy management of thoughts, feelings, actions
- Self-Esteem
 - Overall feeling of one's worth or value
- Self-Efficacy
 - Belief in one's abilities, specifically to meet challenges, complete tasks

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Subskills, Building Blocks?



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"Unifying Theory:" Ability to Direct One's Life



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How to Account for Outcomes?

- Research on post-secondary student retention (e.g., Test et al., 2013)
 - Self-determination skills highly predictive of program completion
 - Being able to make choices, learn to evaluate decisions
 - Engage in goal-directed, self-regulated behaviour
- Hypothesis: Young people who struggle to complete their programs may have underdeveloped skills in self-determination

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Self-Determination Theory (Deci & Ryan, 2004)

- People have inborn tendencies to:
 - Grow and develop psychologically
 - Master challenges
- Achieved only within a supportive social context
 - Knowledge and skills are not enough
 - Trusted others (parents, teachers, hearing care providers, etc.) provide relevant contexts conducive to learning, acquiring skills

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Becoming Self-Determined:

- | | |
|--|---|
| <ul style="list-style-type: none">• Relatedness<ul style="list-style-type: none">• Positive relationships that facilitate motivation, growth• Competence<ul style="list-style-type: none">• Desire to succeed, achieve goals; learn about self, feel in control | <ul style="list-style-type: none">• Autonomy<ul style="list-style-type: none">• Able to make choices, learn to evaluate decisions• Engage in goal-directed, self-regulated behavior |
|--|---|

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Skills Best Learned ...

- Through real-world experience
- With practice and supportive feedback
- By identifying short- and long-term goals



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Self-Determination Interventions: Impacts

- Higher academic performance
(Solberg et al., 2012; Zheng et al., 2014)
- Better quality, quantity of friendships
(Millen et al., 2019)
- Positive transition outcomes
(Collins & Wolter, 2018; Jeno et al., 2018)
- Success in postsecondary education
(Ju et al., 2017; Test et al., 2013; Thoma & Getzel, 2005)
- Increased quality of life
(McDougall et al., 2010; Nota et al., 2011)

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Self-Determination/Children with Disabilities

- Disabilities tend to limit degree to which children become more self-determined
- Children with HL may demonstrate learned helplessness, give up without trying (Seligman, 1972)
 - Due to previous failure, discouragement
 - No opportunities to make choices, decisions
 - Become accustomed to adults providing help

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It All Depends on Opportunity

“Deaf youth often have fewer opportunities to develop self-determination skills.... Opportunities to exercise those skills must be available across a range of settings and interactions. All people have potential for strong self-determined behavior but need **intentional spaces** to make their own choices and practice those skills.”

To download PDF: <https://www.nationaldeafcenter.org/selfdetermination>

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Promoting Self-Determination: An Intentional, Ongoing Process

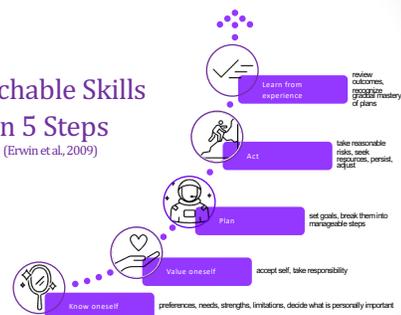
- “Simply growing older does not provide all the needed opportunities to acquire the abilities to make choices and decisions that promote later self-determination” (Erwin et al., 2009, p. 28)
- Children learn SD over time with **facilitation and support** (Guay, 2022)



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Teachable Skills in 5 Steps

(Erwin et al., 2009)



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Examples, ages 2-5: (Luckner & Seabold, 2013)

- Help children identify their preferences, interests
- Provide opportunities to make choices (food, clothing, activities, books)
- Provide opportunities to plan activities that will happen in near future
 - “What do you want to do after you take a nap this afternoon?”
- Discuss activities before, during, and after they occur
- Praise goal-setting, decision-making, problem-solving efforts
- Teach children to take care of their hearing assistive technology
- Have children help with household chores (e.g., setting table, sorting clean laundry)

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<https://www.maine.gov/dhhs/sites/maine.gov/dhhs/files/documents/ocfs/cbhs/documents/Youth%20Transition%20Booklet%202019.pdf>

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“Young Person in Center:” Rights-Based

UNICEF Convention on the Rights of the Child (1989)



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Being “Person-Centered W/Children”

- Engage with children’s expertise about their own lives
 - Personal, social experiences of their care
 - How experiences are affected by relative lack of power in some settings
- Explore children’s understandings, preferences in terms of their physical/health challenges, day-to-day experiences
- Develop resources to engage with even the youngest children beyond conventional assessments (Curtis-Taylor, 2010)

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Child-Friendly Version

convention-rights-child-text-child-friendly-version.pdf



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<p>12 Children have the right to give their opinions freely on issues that affect them. Adults should listen and take children seriously.</p>	<p>13 Children have the right to share freely with others what they learn, think and feel, by talking, drawing, writing or in any other way unless it harms other people.</p>
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- Specifically cited by proponents of child-centeredness in health care
- Requires entities to ‘assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child’

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Not Suggesting Anarchy 😊

- Rather, an effort to support children’s development in healthy, productive ways
- Rights support self-awareness, competency development, self-determination
- Principles underlying this set of rights (James et al. 1998):
 - Child is seen as a reliable reporter of his/her life
 - Child is to be an active participant in the healthcare partnership
 - Care considers the whole child, as well as entire family

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Child Centeredness...

- Is not a “given” in Family-Centered Care models
- Supports children’s right to participate in topics that concern them
- “Five-level model” to ensure that:
 - Irrespective of age, child is listened to
 - Child is supported in expressing his/her views
 - Child’s views are taken into account
 - Child is involved in decision-making process
 - Child can share power, responsibility in decision-making (Söderbäck, 2011)

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“Tensions Inherent in Practice” (Ford et al., 2018)

A girl aged 4 walks into the phlebotomy room with her parents to have her bloods taken for the first time.

As she enters the room, she is quiet and looks worried. Her dad sits down on the chair and puts the girl on his knee and cuddles her around her middle.

The girl sees the equipment and starts saying “no, no, no” and starts to cry, her dad directs the girl to look at her mum across the other side of the room and cuddles her more tightly.



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- The health professional says, ‘don’t worry this will only take a minute’ and takes and holds the girl’s arm while her dad continues to cuddle her tightly so she cannot wriggle around.
- The girl is crying quite loudly when the butterfly is inserted. The procedure took about 30 seconds, a plaster is applied and she is released from the hold.
- The girl continues to be upset for several minutes afterwards and no-one in the room talks directly to her as she continues to sit on her dad’s knee and the health professional sorts the bottles out.
- Mum then takes a magazine out of her bag and says ‘look what I got you’.



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Immediately Appreciate the Tension:

- Child is scared
- Phlebotomist has a job to do
- Parents need to get procedure over with

- Can be seen as just a moment in time, of no special consequence
- Concern: not this moment, but risk of accumulated moments in a child’s development
- Could add up to countless missed opportunities to develop as a person

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Choices While We “Get This Done:”

“How do you want to handle this?”

- Look at me, squeeze my hand hard?
- Count to 10 with me?
- Hum our favorite song together?
- Think ahead to our ice cream plans?
- Poster: what about those kittens?



“Whew, it’s over! That was hard but you did it. How do you feel about it?”

Table compares strengths, challenges of FCC/CCC:

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Table 1. Key strengths and challenges of FCC and CCC.

Strengths and challenges	FCC	CCC
Centre of thinking and practice	Family	Child
Partnership and collaboration	Parents are the focus of the partnership	The child, belonging to a family, is the key and active agent in the partnership
Decision-making	The parents make the formal decisions	The child is recognized as agent with needs and rights to privacy and dignity, involved in decisions affecting their care and based on their competence
Respect and honouring differences	As assessed by the parents for a shared family interest	The child is seen as a social actor with its own rights
Information sharing	The family, and usually based on the parents' views and preferences	The child is included and guided by an adult with opportunity to increase competence
Care planning	Care planned around the family as a unit	Care planned around the child's perspective and preferences
Context of family and community	Care in the context of family and community	Care in the context of family and community

FCC: family-centred care; CCC: child-centred care.

Coyne et al., 2016, p. 496

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Opportunities to Increase Competence

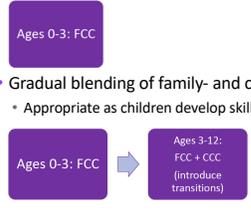
- By school age, children have emerging capacity for logical thought, understanding others' perspectives (Theory of Mind)
- Children want to develop competence, participate in decision-making
- When children's preferences for inclusion are not met or impeded, they feel powerless and depersonalized (Coyne et al., 2018)



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Summary of "Centeredness" Models

- FCC highly appropriate model when infants/toddlers are not capable of speaking for themselves
- Gradual blending of family- and child-centered care
 - Appropriate as children develop skills in self-expression (ages 3-12 years)



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Growing "Child-as-Person" Relationships

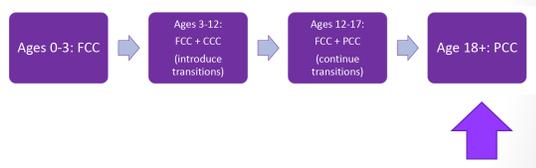
- Approaching young adulthood, CCC → PCC (ages 12-17)



- Planned transition process from Child-Centered to PCC
- Promoting independence, guided practice
 - Decisions, accountability, self-awareness

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Because Ready or Not...



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How To:



- Provide opportunities to speak for themselves, make decisions?
- Increase levels of engagement?
- Provide repeated opportunities, ongoing support, coaching?

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Starting Point: Our Conversational Style?

“Time for new ear molds,
we’ll start with your right ear, here we go.”



“Time for new ear molds,
which ear goes first?”

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Difference: Insignificant?

- In 2nd example, during that moment, child:
 - Is being taken seriously
 - Has power, control over events — no matter how minor
 - Is experiencing an active role in his or her care
- Our challenge: How to extend blink-of-eye moment of CCC?
 - Increase opportunities across childhood, adolescence
 - Ultimately into a standard of care

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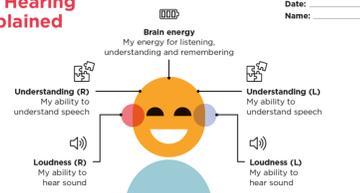
Follow

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Resource Tool: “My Hearing Explained for Children”



My Hearing Explained



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Child Speaks for Self. We Listen.

Age 3-6

My ability to hear sound:

1.

2.

My everyday life:
What I struggle with:

What I can hear:

Who and where would I like to hear better:

Age 6-12

My ability to understand speech:

1.

2.

My next steps:
Technology to help me:

What can I do to hear my best:

Age 12+

My energy for listening:

1.

2.

How can others help me hear my best:

Other:

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App: “The People I Talk To For Teens”

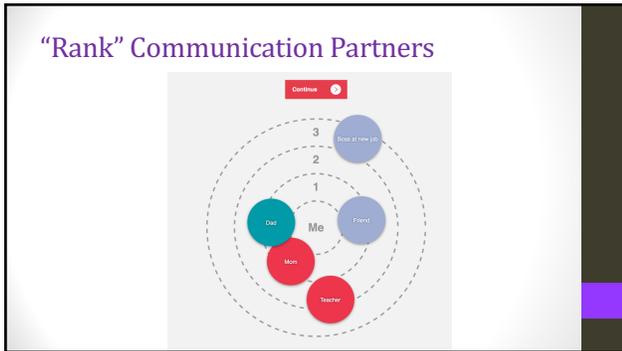
- Completed independently by teen
- Takes about 5-7 minutes
- Is sent electronically to clinician or saved as PDF
- Discussion led by teen

Select the people you talk to most often. Choose from the list below or add your own.

Mom Dad Sister Friend Doctor Classmate Teacher Brother Grandparent

Boss at New Job Add your own

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Provide Some Details

My Notes

- Describe your communication with each person you've selected: mom and dad: we communicate fine. Friend and teacher, usually fine, sometimes misunderstandings. New boss, don't know yet, am a little worried
- Which situations are the most challenging? New job is in a noisy place, lots of people talking
- Which situations are easy? home and most of school
- List three things you would like to discuss with your hearing care provider that would help you improve your communication with the people you talk to: How to explain issues with new boss. Will she fire me?

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Review, Save, Send

Discuss at appt.

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- ### What Transpires?
- Audiologist creates an "intentional space"
 - Young person/child in "center of care"
 - Views given due weight in accordance with age and maturity – and documented
 - Treatment plan supports self-determination skills
 - First recognizes child's "person-ness"
 - Second recognizes her "family-ness"

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For More Info: (1) Idainstitute.com

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Recently: Pediatric Grand Rounds (n=6)

- Details:
 - Age, gender
 - Family history
 - Pathology, treatments, outcomes...

No "child voice" reported

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The Laryngologist
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Cochlear Implantation in Children with Single-Sided Deafness

Nicholas L. Deep, MD, MPH, Steven A. Gordon, MD, MPH, William H. Shapiro, AuD, Susan B. Waltzman, PhD, J. Thomas Roland Jr MD, David R. Friedmann, MD, MSc

https://www.researchgate.net/profile/Nicholas_Deep/publication/339320765_Cochlear_Implantation_in_Children_with_Single-Sided_Deafness/links/5e8c708092851c2f5286c1a2/Cochlear-Implantation-in-Children-with-Single-Sided-Deafness.pdf

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TABLE II
Speech Perception Testing

Subject	Pre-Op				Post-Op*				Follow-up (years)
	WRS Ear to be Implanted (Aided)	WRS Bilateral	SNR Ear to be Implanted (Aided)	SNR Bilateral	WRS CI Only	WRS Bilateral	SNR CI Only	SNR Bilateral	
S1	0	84	0	1	4	88	1	97	6.0
S2	29	100	49	1	20	100	49	100	1.2
S4	0	96	0	1	32	100	70	100	2.9
S5	CNT	CNT	CNT	CNT	72	92	98	100	3.1
S6	CNT	CNT	CNT	CNT	84	92	1	1	3.5
S7	0	100	0	1	80	100	94	98	3.1
S8	0	96	0	90	88	100	95	94	1.8
S9	36	90	1	94	70	100	96	89	1.2

TABLE III
Sentence in Noise Testing with CI "On" vs. CI "Off"*

Subject	S/Nr CI Off	S/Nr CI On	S/N _{off} CI Off	S/N _{off} CI On	S/N _{off} CI Off	S/N _{off} CI On
S4	100	100	100	100	94	100
S5	98	98	100	98	100	100
S7	100	100	98	100	100	100
S8	80	90	80	100	90	100
S9	89	89	85	96	90	95

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TABLE I
Demographics

PTA of better Ear	Etiology	Onset (Age at Diagnosis)	Age at CI (years)	Duration of Deafness (years)
12	Bilateral EVA	Acquired (0 yo)	9.8	7
13	Hereditary	Congenital	6.2	6.2
15	Cochlear Nerve Aplasia	Congenital	6.3	2.4
13	Idiopathic	Congenital	3.0	3
15	Idiopathic	Congenital	1.2	1.2
25	Bilateral Mondini*	Congenital	1.4	1.4
20	Idiopathic	Congenital	3.0	3
10	Idiopathic	Acquired (2 yo)	4.4	2.4
15	Idiopathic	Acquired (2.8 yo)	3.9	1.1
15	Idiopathic, Suspected Genetic	Acquired (8.3 yo)	9.3	1
15	Idiopathic	Acquired (4 yo)	4.4	0.6
18	Idiopathic	Acquired (0 yo)	11.8	6
25	Congenital CMV	Congenital	1.0	1.1
10	Idiopathic	Congenital	5.2	5.2

- No pre-implant "child voice" reported
- "If it isn't documented, it didn't happen"
- No protocol on collecting child-centered data

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Everyone's Challenge: How to Solicit Child Input / Support Self-Determination?

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Getting the Most Out of IEPs

An Educator's Guide to the Student-Directed Approach

Colleen A. Thomas & Paul Wehman with invited contributors

IEP Individualized Education Program

THE INFORMATION CONTAINED ON THIS REGULAR SCHOOL FORM IS INTENDED TO BE USED BY STATE-APPROVED SPECIAL EDUCATORS.

DATE: _____

NAME: _____ GRADE: _____

ADDRESS: _____ CITY: _____ STATE: _____ ZIP: _____

DATE OF BIRTH: _____

SCHOOL OF RESIDENCE: _____ COUNTY OF RESIDENCE: _____ DISTRICT OF SERVICE: _____

IS THIS CHILD A MEMBER? YES NO

WAS THIS CHILD IN SCHOOL BEFORE THE END OF HIS/HER LAST YEAR? YES NO

IS THIS CHILD UNDER 18 YEARS OF AGE? YES NO

IS THIS CHILD A MEMBER OF THE IEP TEAM? YES NO

IF YES, PLEASE PROVIDE THE NAME OF THE MEMBER: _____

IF BY THIS DATE? IF YES, PLEASE PROVIDE THE DATE: YES NO

MEETING INFORMATION

MEETING DATE: _____

MEETING TIME: _____

MEETING LOCATION: _____

MEETING AGENDA: _____

MEETING PARTICIPANTS: _____

MEETING CHAIR: _____

MEETING MINUTES: _____

MEETING NOTES: _____

MEETING EFFECTIVE DATE: _____

MEETING END DATE: _____

MEETING REVIEW DATE: _____

MEETING REVIEW BY: _____

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Handout Example (Shogren et al, 2019)

The Self-Determined Learning Model of Instruction (SDLMI) Teacher's Guide

SDLMI
Self-Determined Learning Model of Instruction

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From Intro:

- Being self-determined is about acting as the *causal agent* in one's life
- Causal agents have skills and attitudes that enable them to make or cause things to happen in their lives
- People who are self-determined:
 - Self-initiate
 - Self-regulate actions to solve problems, make decisions
 - Set goals that impact their lives

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The Self-Determined Learning Model of Instruction: Student Questions – Phase 1 – Set a Goal

Name Luca Date September 17
(Date Phase 1 Began)

What is my goal? Let's try to identify something that you want to learn or improve on.



Please answer the questions below.

1. What do I want to learn or improve on?

I want to get my reading done before class so that I know what I'm talking about during class. Also, I know I'll need to read every day as a magazine editor.



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2. What do I know about it now?

I don't consistently read for class – sometimes I do, sometimes I don't. I'm really busy with other things like friends and sports.



3. What must change for me to learn what I don't know?

I need to plan when I'm going to read and learn how to take better notes about my reading. I can't get distracted by my phone, either.



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4. What can I do to make this happen?

I can use a planner to keep track of my assignments and when things are due.

I could try to schedule a time to read before class too.



I have listed a specific, measurable activity for student question 4. This is my goal, the activity I will be working on during Phase 2 and Phase 3.

End of Phase 1 Go on to Phase 2

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The Self-Determined Learning Model of Instruction: Student Questions – Phase 2 – Take Action

Name Luca Date October 12
(Date Phase 2 Began)

What is my plan? Let's think about how to achieve the goal that you set.

Please answer the questions below.

5. What can I do to learn what I don't know?

I can talk to other people like my classmates and teachers to figure out how they plan when and where to read and keep track of assignments. Then I can check in with Ms. Whitmore and Mr. Elliott about the best thing to do.



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6. What could keep me from taking action?

I have practice every day for sports. When I'm done with that I want to hang out with my friends, and that's not going to change. Plus it's going to be harder because Ms. Whitmore says we have a lot of stuff due at the end of the semester.



7. What can I do to remove these barriers?

I need to find a time to do my reading because I'm really busy with sports and friends – maybe a calendar would help. I also need to be more focused on my work at night instead of my phone and computer.



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8. When will I take action?
 I guess I'll start tomorrow.

End of Phase 2. I will start working on my Plan and then go on to Phase 3.

End of Phase 2 → **Go on to Phase 3**



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**The Self-Determined Learning Model of Instruction:
 Student Questions – Phase 3 – Adjust Goal or Plan**

Name Luca Date December 3
 (Date Phase 3 Began)

What have I learned? Let's think about whether or not you achieved your goal.

9. What actions have I taken?
 I've been putting my assignments in my planner and getting my reading done most of time. I talked to my teachers for help with taking notes, but I haven't decided if it's going to work for me.



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10. What barriers have been removed?
 I'm doing better with my scheduling. I told my friends and family when I'm going to be doing work. It helps that my friends have their own goals, too. I like reading after dinner, but my phone is still sort of a problem.

11. What has changed about what I don't know?
 I think scheduling works for me, but my teachers still have to remind me to do it sometimes. I'm going to use this next semester, too, when there's more assignments.




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12. Do I know what I want to know?
 I wanted to do better in English, and I'm getting more of my reading done. Scheduling helped. My parents and teachers still think I'm on my phone too much, so I might think about working on that next.

Did I finish my goal? Please mark in the bubble X Yes No

IF YES
 How did I feel about the results? Good! I'm managing my time and work better.
 Now I will go back to Phase 1 and set a new goal.

IF NO
 I will look back at Phase 1 again. If the goal is still a good one for me, I will move on to Phase 2 to revise my plan **OR** I can rewrite my same goal or change it to a new goal.



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Parting Words of Wisdom

"Treat children as though they already are the persons they are capable of becoming."


 Haim Ginott

"In every child is the seed that will mature into an adult."


 Maria Montessori

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Thank You!

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