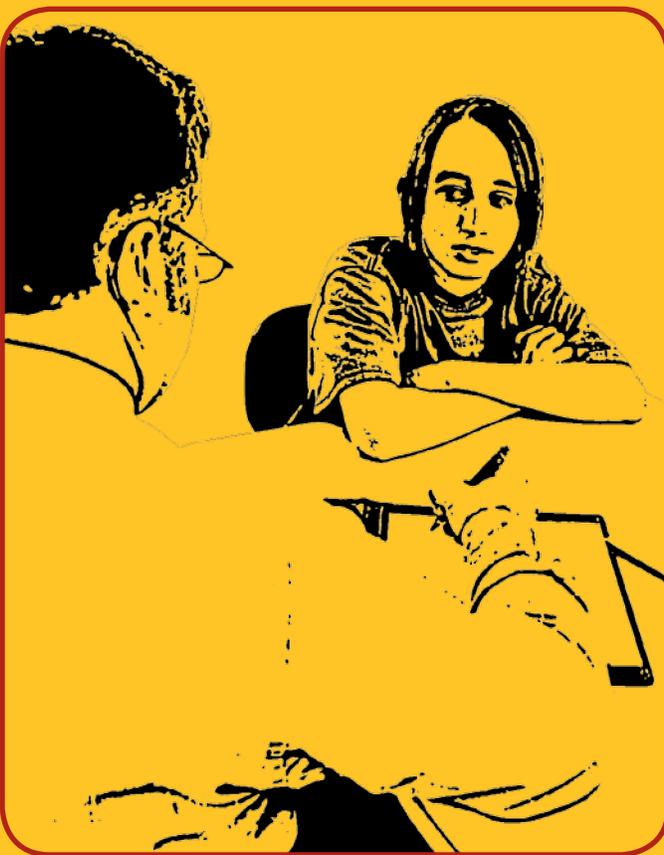


# Involving Youth in Planning for Their Education, Treatment and Services:

## Research Tells Us We Should Be Doing Better



Youth Empowerment



## Acknowledgments

This publication was produced by the Research and Training Center on Family Support and Children's Mental Health at Portland State University and was developed with funding from:

the National Institute on Disability and Rehabilitation Research, United States Department of Education, and



the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (NIDRR grant H133B040038).

The content of this publication does not necessarily reflect the views of the funding agencies.

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## Suggested Citation

Walker, J. S., & Child, B. (2008). *Involving Youth in Planning for Their Education, Treatment and Services: Research Tells Us We Should Be Doing Better*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

## Introduction

**H**uman service and educational agencies often convene teams to work collaboratively on plans for serving children or youth. This happens most often for children and youth who are involved with multiple systems or who are felt to be in need of intensive support. Often, these are children and adolescents with cognitive, emotional, behavioral, physical, or learning challenges.

The teams that create plans for these young people include IEP (Individualized Education Plan) teams, wraparound teams, foster care Independent Living Program teams, transition planning teams, youth/family decision teams, and other teams that create service, care, or treatment plans. Unfortunately, it is often true that these plans are created *for* youth, with little input or buy-in from the young people themselves.

Many adults support the idea of increasing youth participation in planning and decision making about their own care, treatment, and preparation for the future. Other adults just think this is a bad idea. Most adults are probably somewhere in between, however. They think it's a good idea in general, but maybe not for youth who have emotional problems (participating in meetings is too stressful), youth who have behavioral problems (they will



act out and cause planning meetings to be unproductive), youth with cognitive challenges (their level of functioning is too low for them to really participate), or youth who have difficult personal circumstances (hearing the truth about their lives will upset them).

While there is not as much published research on this topic as there should be, the research that is available indicates that involving youth meaningfully—and successfully—in planning for their own treatment and care is quite possible. This research also indicates that involving youth meaningfully in planning provides benefits for the youth and his or her caregivers and providers.

Following are some common questions that people might have about youth participation in education, care, treatment, or service planning. Information from published research is summarized to help answer each question. We provide references so that if you are interested, you can get more details from the original sources.

**Q**uestion: Before we get into these other questions, what do you mean by “meaningful” participation in education, care, service or treatment planning?

**Answer:** *First of all, if a youth is going to participate in planning, he or she must be present when plans are made. But merely having the youth present doesn't mean that his or her participation will be meaningful. Participation isn't meaningful unless a young person is able to have an impact on the decisions that become*

*part of the plan. So even a youth who talks a lot during a meeting may not really have an impact on what is decided.*

**Detail:** By “meaningful participation,” we mean that a young person has the opportunity to make real choices for the plan and to influence decision making. To participate meaningfully, the young person must also have access to information that enables him or her to make informed choices and decisions. He or she also has the opportunity to help set and monitor the goals that become part of the plan. Finally, the young person has the encouragement and support needed to take an active role in planning.

**Q**uestion: Aren't young people already involved in their education, care, and treatment planning?

**Answer (part 1):** *This is a long answer, so let's take it step by step. First of all, it appears that few students participate meaningfully in creating their Individualized Education Plans (IEPs).*

**Detail:** Much of the research that helps answer this question comes from examining student participation in creating their Individualized Education Plans (IEPs). Federal legislation requires that high-school-aged children participate in the IEP process as

part of planning for transition to adulthood. Despite this mandate, it seems that most students do not participate meaningfully in the IEP/transition planning process. Many do not even have a transition plan, and many students who attend their IEP meetings do not participate at all.

The largest study to examine this issue was done by Wagner<sup>1</sup>, who analyzed data on a nationally representative sample of 1,077 students, aged 13-16 years old. All the students were receiving special education services and had been given the label of “emotional disturbance.” (This is the label that applies to children with emotional or behavioral disorders.) Between 15% and 35% of eligible children

did not even have transition plans at all. Among those who did, 16% had not attended their last transition planning meeting, and another 27% had attended but not participated at all. Only about one in ten youth in the study had participated “substantially” in their most recent transition planning meeting.

Powers and her colleagues<sup>2</sup> analyzed 400 IEPs and transition plans of students in Oregon and California. About a quarter of the time, students were not present at the planning meeting. Students were often assigned responsibility for carrying out the goals on their plans, even if they had not been at the meetings when the plans had been made. Only about one fifth of the goals on the plans appeared to be rooted in a student’s interest or preferences.

Lovitt and Cushing<sup>3</sup> interviewed students with IEPs at two high schools in Washington state. They found that most students were unfamiliar with the IEP process and felt no ownership of their plans. Among students who had attended their IEP meetings, most students said they “just sat there.” The researchers also examined the students’ IEP plans. While the documents were well prepared and met federal guidelines, “a lack of individualization was obvious.” Many of the plans had exactly the same goals.

**Answer (part 2):** *It also seems that youth with emotional or behavioral disorders do not usually participate meaningfully in creating their own care, treatment, or service plans.*

**Detail:** Gyamfi<sup>4</sup> conducted research on federally funded projects to create “systems of care” for children and adolescents with complex mental health and related needs. One of the hallmarks of a system of care approach is that youth are to be involved in decisions at all levels of the system, from their own plans to making policy. The study found that youth involvement was limited and that “only in some cases were they involved in planning their services or providing feedback on the services they receive.” In fact, the study also found perceptions that some administrators were actively trying to prevent youth from finding out about their rights and their opportunities to be involved in planning.

Walker and Schutte<sup>5</sup> observed wrap-around planning meetings around the country and found that the youth who was the focus of planning was present (for more than half of the meeting) just over a third of the time (39%).

**Answer (part 3):** *Professionals who participate in this kind of planning are also dissatisfied with the level of youth participation.*

**Detail:** Analyzing post-meeting surveys from the wrap-around meetings they observed, Walker and Schutte<sup>5</sup> found that the most common dissatisfaction with the meeting was with the level and/or nature of youth participation. In a study of IEP meetings, Mason found only 34% of school personnel were satisfied with the level of student involvement.<sup>6</sup> Adults are often uncertain about how to involve youth productively in the planning process.<sup>3, 5, 7, 8</sup>

**Q**uestion: You said before that participating meaningfully in planning means that young people have to take part in making decisions and setting and monitoring goals. Can youth who have significant mental health, learning, and/or cognitive difficulties really be expected to master the skills needed to do this?

**Answer:** *Yes. Children and youth of all ages and with a variety of disabilities and challenges have successfully learned skills and participated in planning.*

**Detail:** This is an area where a lot of research has taken place. A large number of curricula have been developed for teaching young people skills that are important for meaningful par-

ticipation in planning, including skills for self-advocacy, self-determination, problem solving, choice making, and goal setting and monitoring. These skills have been successfully learned and used by children as young as five years old, and by students with a variety of disabilities and disorders including mild and moderate cognitive disabilities, emotional and behavioral disorders, learning disabilities, and physical disabilities. There are a lot of these studies, so if you want to know more about them, the easiest place to begin is with published articles that review the existing evidence.<sup>9-12</sup>

There is also quite a bit of evidence that children who are taught these kinds of skills participate more, and more meaningfully, in planning. Again, this has been shown for children and youth with cognitive disabilities, learning disorders, emotional and behavioral disorders, and physical disabilities.<sup>7,8.</sup>

**Q**uestion: Why do you think it's so important to include young people in planning for their education, treatment or care? What's to be gained?

**Answer (part 1):** *There are a lot of potential benefits to increasing youth participation in planning, so let's think about different kinds of benefits one at a time. First of all, when people feel they are doing something because they want*

*to, they tend to be happier and more engaged, and do a better job, than when they don't feel they have a choice.*

**Detail:** There is a wealth of research that compares the experiences of people who feel they are acting autonomously—by their own choice—and those who are externally controlled. People acting autonomously tend to have more interest, excitement and confidence about what they are doing. In turn, this leads to enhanced performance, persistence, and cre-

ativity.<sup>16</sup>

There's also a whole lot of research that looks at this issue specifically in relation to people's work on teams—usually this means teams created in the workplace. Not surprisingly, this research shows clearly that team members are much more likely to be invested in team goals and to follow through with team tasks if they feel that they participated meaningfully in selecting the goals and making decisions about how to achieve the goals. Likewise, when the members of a team all agree on the goals, the team is more likely to achieve the goals.<sup>17, 18</sup>

A main task of later childhood and adolescence is to develop autonomy. There is quite a bit of research showing that an adolescent's ability to make choices about the activities he or she is involved in has a direct impact on mood and well-being.<sup>19</sup> Adolescents also perform better on activities they choose themselves.<sup>19</sup> In a small study focusing specifically on students with emotional and behavioral disorders, making choices increased task engagement and reduced disruptive behavior.<sup>20</sup>

In short, it makes sense to think that if youth feel they are making choices for their plans, they will be happier, try harder, and do better when they are involved in activities that are part of the plan.

**Answer (part 2):** *Learning to make plans and achieve goals is an important part of growing up for any young person. People who are confident that they can solve problems in their lives and reach the goals they set for themselves experience many positive out-*

*comes—including positive emotional and behavioral outcomes.*

**Detail:** There are a large number of studies that examine the positive outcomes that are associated with *self-efficacy*. Self-efficacy is the confidence that people have about their ability to overcome obstacles in their lives and to reach goals they set for themselves. People develop self-efficacy in large part because of having successful experiences using their own skills and resources to achieve personally meaningful goals. Similar outcomes have been found in studies that examine optimism and hopefulness, which also have a lot to do with people's beliefs that they can achieve the goals they set for themselves.

Because there are so many studies that affirm these kinds of findings, we'll mention some that are particularly relevant, but mostly we'll refer to reviews that summarize findings from multiple studies. People with higher self-efficacy tend to be more optimistic and hopeful, and they persist and try harder in the face of obstacles.<sup>21-23</sup> People who believe they can solve problems in their lives have better general mental health and well-being, and they are more likely to avoid depression.<sup>21, 23-26</sup> In general, people with higher self-efficacy cope better with stressful life circumstances. They are also more likely to take action to protect their health; to adopt new, healthy habits; and to maintain behavior change.<sup>21, 25</sup> Adolescents who are optimistic tend to do better in school and college, abuse drugs less, and have less anger, better health, and fewer social problems.<sup>27</sup> Children and adolescents who are trained in problem-solving have more

## What's to be gained? (Continued)

optimism and avoid depression.<sup>28</sup>

There is also some relevant research looking at *self-determination* among adolescents with various kinds of disabilities. (Self-determination involves taking action to make decisions and exert some control over one's life.) In one study, adolescents with cognitive and/or learning disabilities who were higher in self-determination had better post-school outcomes, including being more likely to live independently, have a bank account and pay for their own groceries.<sup>29</sup> In another similar study, students higher in self-determination also had better post-school outcomes. They were more likely to be employed and earned more per hour than peers who were low on self-determination.<sup>30</sup> Other studies are described in the review by Chambers.<sup>12</sup>

Finally, there are studies that have shown that it is possible to increase self-determination among youth with disabilities—including youth with emotional and behavioral disorders. For example, youth with disabilities who participated in an intervention called *Take Charge*, which taught self-determination skills and provided mentoring for youth, showed higher self-determination and increased goal achievement.<sup>31</sup> Wehmeyer developed the Self-Determination Model of Instruction and found that it was effective in promoting self-determination and enabling students to attain educationally valued goals.<sup>32</sup> In a study by Zhang, a group of ninth graders with learning disabilities completed a curriculum on self-determination. These students gained significantly more on measures of self-determination skills

than students in a control group.<sup>33</sup>

Taken together, these studies tell us that it makes a lot of sense to try to increase self-determination and self-efficacy among youth who are involved in collaborative team planning. We know that young people can learn the skills for solving problems, making decisions, and creating and monitoring plans, and that this contributes to their self-determination and self-efficacy. It also seems very reasonable to think that self-determination and self-efficacy would increase when youth play an important role in helping the team successfully achieve goals on the plan. Furthermore, the most powerful source of self-efficacy is the experience of success in reaching self-defined goals.<sup>21</sup> When participation on teams helps youth have these experiences, it is likely to increase their self-efficacy.

**Answer (part 3):** *Developing self-efficacy would seem particularly important for youth who face high levels of challenge in life. However, it appears that children with disabilities and children who are involved with the child welfare or mental health systems have far fewer opportunities than their peers to experience self-efficacy.*

**Detail:** As we said before, the most powerful source of feelings of self-efficacy is the experience of success in reaching self-defined goals.<sup>21</sup> Children and youth who experience challenges in their lives—either from difficult personal circumstances or from having disorders or disabilities—often do not have many opportunities to experience this kind of success.<sup>34-37</sup>

In a qualitative study with boys in the child welfare system in England, Leeson<sup>38</sup> found that the boys had “overwhelming feelings of helplessness experienced as a consequence of not being involved in decision-making.... The boys were all scared of making decisions [and] did not know how to make them.” One boy described the anxiety he had about making wrong decisions, and felt that he could not rely on his own thought processes.

In another study of young people’s perceptions of mental health services, young people emphasized the lack of control they had, and how that made them resist help that was offered: “I’ll get mad if a social worker turned round to me and says: ‘You’ve got to do this, you’ve got to do that. They’ll wind me up and I’ll get mad and then I’ll just flip on ‘em.’ ”<sup>39</sup>

So it should be particularly important to help youth who experience challenges in life have successful experiences of planning and achieving

valued goals.

**Answer (part 4):** *In addition to all these reasons, perhaps the most important reason for including youth meaningfully in planning is because it’s the right thing to do.*

**Detail:** Virtually any declaration of human rights is based in the idea that people have the right to make choices about their own lives, and that the only time that it is reasonable to restrict that right is if one person’s choices are likely to lead to harm. As human beings, we acknowledge we have a moral duty to promote this essential aspect of freedom.

Additionally, we owe it to our young people to do our best to help them become successful, autonomous adults who are capable and confident in making good decisions for their lives. Research like that described here provides clear guidance about how we can fulfill this duty to our children and youth.

**C**onclusion: Ok, let me see if I have this right. What you’re saying is that it’s possible to teach youth to participate meaningfully in their education, treatment, or care planning. Doing that helps youth achieve better outcomes, and probably also helps the adults who work with the youth get better results as well. So we should do what we can to help youth participate meaningfully because it gets good results. And above all, it’s the right thing to do.

**Answer:** *I couldn’t have said it better myself.*

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# ACHIEVE AMP PLAN



Self-Determination



*This document was created by staff and advisors of the AMP (Achieve My Plan) project at the Research and Training Center on Family Support and Children's Mental Health, Portland State University, Portland, Oregon.*