



PATH: Parent activities toward healthy self-determination

Tammy V. Abernathy
Ann Bingham

A Feature Article Published in

TEACHING Exceptional Children Plus

Volume 6, Issue 1, October 2009

PATH: Parent activities toward a healthy self-determination

Tammy V. Abernathy
Ann Bingham

Abstract

PATH: Parent Activities toward Healthy Self-Determination was developed as a tool for parents to evaluate their personal status in coping, knowledge of disability related issues, and advocacy. This article describes PATH's five reflective, non-judgmental activities resulting in an opportunity for parents and family's to self-assess progress in developing their child's self-determination. The activities are designed to inform parents and generate ideas and conversations within families and with school personnel. The activities, while scored, are not to be judged or evaluated. Examples from two families with varied levels of knowledge in disability issues are included in the article. Teachers and case managers are urged to share these tools with parents of school-age children with disabilities.

Keywords

Self-determination, self assessment, parents

Acknowledgments:

The authors wish to express appreciation to Dan Dinnell and Marcia O'Malley for sharing their expertise.

SUGGESTED CITATION:

Abernathy, T. and Bingham, A. (2009). PATH: Parent Activities toward a Healthy Self-Determination. *TEACHING Exceptional Children Plus*, 6(1) Article 4. Retrieved [date] from <http://escholarship.bc.edu.education/teclus/vol6/iss1/art4>

Purpose

PATH: Parent Activities toward Healthy Self-Determination was developed as a tool for parents to evaluate their personal status in coping, knowledge of disability related issues, and advocacy. PATH engages parents of school-age children with disabilities in a set of five reflective, non-judgmental activities resulting in an opportunity to self-assess their progress in their child's self-determination development. The tool is intended **solely** for personal reflection and as a means for assessing individual responses to their child's disability and the parent and child's progress toward self-determination.

The PATH experience positions parents in the role of evaluator and leaves interpretation of the results in the hands of the parent within the context of their family. Families are encouraged to use the PATH for self-assessment several times throughout their child's development. It is our goal that the accomplishments marked on PATH be internalized as a coping mechanism during future stressful situations. Similarly, it is anticipated that parents will recognize new opportunities that could enhance their own ability to promote self-determination. Teachers and other professionals are encouraged to facilitate this process with the families in their caseload.

Background

One of the most significant challenges parents of children with disabilities face is coping with the child's diagnosis (Gray, 2006; Trute, Hiebert-Murphy, & Levine, 2007). Coping is defined as "cognitions and behaviors used by the individual in evaluating stressors and in initiating activities with the aim of decreasing their impact" (Margalit, Raviv, & Ankonina, 1992, p. 202). Richard Lazarus, a pioneer in studying coping strategies explains that cognitive processes determine the inten-

sity of emotional reactions to the child's disability and that these processes also underlie coping activities (Lazarus, 1998). Thus, parents may respond with either cognitive- or emotion-based coping responses during times of stress. Interestingly, Hartshorne (2002) finds that professionals may mistakenly label parents' hope and courage for denial. Therefore we maintain that parents are in the best position to evaluate their own status regarding coping.

One of the most valued cognitive-coping responses involves seeking information. Turnbull, Turnbull, Erwin, & Soodak (2006) indicate that "families will be more empowered to help their children and themselves when they have access to relevant information" (p. 215). Information may be sought regarding their child's diagnosis, services that are available, and the guarantees that are provided to them under the law. Scorgie and Wilgosh (2007) indicate that as parents become more informed, this information helps them to (a) collaborate with professionals, (b) connect with other parents or support groups, and (c) utilize other sources of support. These authors further indicate that as children age and parents become more familiar with understanding and navigating the service system, they become "active in disseminating their knowledge and skills to parents of children newly diagnosed" (p. 111). Thus, the more knowledge parents obtain, the better they position themselves to be able to advocate for their own and their child's rights and to extend their knowledge to other parents.

The power of parental advocacy is evident when examining the progression of laws providing for the education of students with disabilities. The current special education laws resulted from intense, sustained advocacy by parents willing to press for their

children's educational rights (Siegel, 2001) For most parents, advocacy begins at the local level (Taber, 2007) with teachers and school administrators as parents "attempt to support their children's individual needs, seeking justice in the form of equal opportunities for their children" (Hess, Molina, & Kozleski, 2006, p. 156). This level of advocacy is especially evident during IEP meetings. Many parents subsequently move their advocacy efforts to state and federal legislation (Turnbull, Turnbull, Erwin, & Soodak, 2006).

Development of PATH Activities

The PATH activities described below were developed in three distinct phases. It was essential that parents who have children with disabilities assist in the development of the surveys and field test all of the activities. In phase one survey items were generated through a review of the literature. Items were focused in the areas of knowledge, coping, and advocacy and this focus kept the item pool manageable. After a draft of the items for each survey was constructed we contacted a father of a child with a disability to start the item review process and assess the content validity of the items. This particular father is considered by parents who have children with disabilities as one of the most knowledgeable parent advocates in the state. His perspective, as an expert in the field and as someone who works with families everyday and understands their needs and struggles, made him an excellent item reviewer. Our item reviewer examined the surveys for clarity, authenticity, parent friendliness, and alignment with the topic (Coping, Knowledge, Advocacy). This rigorous process examined every word in every item. Based on the opinion of our expert reviewer several changes were made to the surveys and the scoring process.

After our initial review, we started phase 2 of the development process and conducted a second round of parent field review. This time we were interested in parents' perspectives and the effectiveness of the self-evaluation component of the activities. Ten mothers of children with a variety of disabilities volunteered for this phase of field testing. Specifically, the purpose of this phase of the field review was to eliminate any sense parents may develop during the activities that they were being evaluated by anyone other than themselves. Any thoughts or feelings parents had that suggested professionals were evaluating them had to be eliminated. This was a lengthy process. Each item was reviewed by the field test mothers to validate their clarity, authenticity, and parent friendliness and changes were made when items did not "feel right." Finally, to complete the field test, the feasibility of educators facilitating rather than controlling the PATH process was examined. Parents were asked to describe the educator's ability to encourage the PATH process rather than make evaluative and/or judgmental statements about where parent's scores fell on the PATH or what the scores meant. Because interpreting data is a critical skill for educators it was important to determine if educators could withhold their tendency to interpret data during the PATH experience.

PATH Activities

The PATH is comprised of four parent activities related to Coping, Knowledge, and Advocacy: (1) self-assessing using three true-false survey instruments, (2) scoring the results, (3) recording results on the PATH, and (4) responding to the follow-up questions for personal reflection. PATH is a self-contained set of activities that may be available for use during group activities or taken individually.

**Figure 1:
Activity 1- PATH Surveys**

COPING ©

As you read each of the statements, respond in terms of your overall beliefs and/or behaviors. Please answer True or False for each of the statements below.

As a rule:

T or F

1. I spend time wishing things would be better.	
2. I struggle to admit my child has challenges.	
3. I am reluctant to ask for support.	
4. I often blame myself for this situation.	
5. I continue to question why my child has these challenges.	
6. I know how to find information for myself when I need it.	
7. I tend to put things off – I will think about it tomorrow.	
8. I find myself thinking, “Its not as bad as everyone thinks”	
9. I reach out to others in similar situations.	
10. I keep constantly focused on meeting our family’s next challenge.	

KNOWLEDGE ©

As you read each of the statements, respond in terms of your overall knowledge and/or behavior. Please answer True or False for each of the statements below.

As a rule:

T or F

1. I under stand my child’s diagnosis.	
2. I know what it means to have my child education in the Least Restrictive Environment with appropriate supports.	
3. I don’t participate in the development of the goals and objectives on my child’s IEP.	
4. I know why my child qualifies for special education services under federal law.	
5. I am not aware of a range of potential strategies for teaching my child.	
6. I am aware that professionals other than my child’s teacher may work with my child (e.g. speech language pathologist, occupational therapist).	
7. I do not understand my due process rights.	
8. I do not understand my child’s due process rights.	
9. I understand what it means for my child to have an unbiased educational evaluation.	
10. I know that I have the right to bring whomever I wish to my child’s IEP meeting.	

Figure 1: (Continued)
Activity 1- PATH Surveys

ADVOCACY ©

As you read each of the statements, respond in terms of your overall behavior and/or practices. Please answer True or False for each of the statements below.

As a rule: **T or F**

1. I collaborate and share ideas with my child’s teacher.	
2. I rely on others to advocate for me and my child.	
3. Within reason, my child understands his/her disability.	
4. I ask for evaluations of my child in areas where I have concerns.	
5. I understand that I may veto any item on my child’s IEP, including placement (where my child is taught)	
6. I encourage my child to ask teachers for accommodations and modifications.	
7. I do not take advantage of trainings to help me learn about the IEP process.	
8. I encourage my child to participate routinely in his/her IEP meeting.	
9. I inform my legislators of my concerns about disability issues.	
10. I share my expertise with others.	

Activity 1.

Parents complete three 10-item surveys for Activity 1. There is one survey for each domain in the PATH: Coping, Knowledge and Advocacy. Each item is forced choice with a true or false option. The surveys are designed to have parents respond according to their typical beliefs and behaviors. The survey instructions use the phrase, “As a rule....” to give parents a context for each question.

See Figure 1 for the complete of set of PATH Surveys.

Activity 2

Parents self-score their surveys for Activity 2. Using the PATH SCORING GUIDE (See Figure 2), a parent looks for matches between their surveys and the scoring guide. The instructions inform parents that a match does not indicate a correct response. There are no correct or incorrect responses. The completed surveys are aligned with the color-coded domain (Coping, Knowledge, Advocacy) on the scoring guide. If a survey response matches the response on the PATH SCORING GUIDE, parents mark a mountain symbol ^^ (since we are on a PATH) in the corresponding box. This is done for each survey. Next, the number of ^^symbols in each column is tallied and the number is recorded in the box marked “Total”.

Figure 2
Activity 2 - PATH
SCORING GUIDE

COPING	
Score	^^

KNOWLEDGE	
Score	^^

ADVOCACY	
Score	^^

F	
F	
F	
F	
F	
T	
F	
F	
T	
T	
Total	

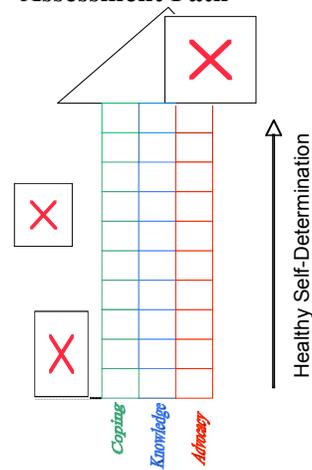
T	
T	
F	
T	
F	
T	
F	
F	
T	
F	
T	
T	
Total	

T	
F	
T	
T	
T	
T	
F	
T	
T	
T	
Total	

Activity 3

Activity 3 helps parents visually make sense of their results. Using the ASSESSMENT PATH (See Figure 3), parents record the results from the PATH SCORING GUIDE onto the ASSESSMENT PATH. Beginning at the bottom of the PATH, parents count up the number of squares equivalent to their score in a domain and color in the grid. For example, if a parent scores 6 in the Coping domain, she would count up six boxes and color in six boxes to begin building a bar graph. The procedure is repeated for each domain.

Figure 3
Activity 3 - Assessment Path



Activity 4

In Activity 4 parents are asked to respond to follow-up questions designed to self-assess their satisfaction with their ratings within the current context of their family situations. Because family situations are always evolving it is possible that a parent may be pleased with their results the first time they complete the PATH but dissatisfied another time. Parents may also have a high score in one area (knowledge) and a lower score in another (coping); they may determine that they would like to improve their weaker area. Or parents may decide that their scores are satisfactory given a particular family issue they are currently facing. It is this personalized, self-assessment feature that makes the instrument valuable to parents. See Figure 4 for Activity 4.

The role of professionals in the PATH is unusual. The activities were *not* designed for professionals to offer opinions about the results or to evaluate parents' levels of self-determination. Professionals are encouraged to introduce the PATH to parents as a means to encourage dialog within families. Further,

Figure 4: Activity 4 - Reflection Follow-up:

The *Assessment PATH* should give you information about how your behaviors are helping your child move toward self-determination. The *PATH* is divided into three sections. Your scores in each of the three areas (Coping, Knowledge, Advocacy) are highly personal and hold meaning only for you and your family. The goal of the *PATH* activities is to give information to help you self-assess yourself as you help your child progress toward a more self-determined future.

It is likely that you will score in different places in each lane of the *PATH*. Also, the meaning of the score is a function of the age and developmental level of your child, and your personal goals. There is no right place to score on the *PATH*. The *PATH* is purely informative and the only one who makes a judgment about the scores, is you.

As the final activity, please respond to each of the questions below.

1. In what way do your placements on the *PATH* reflect your current abilities to cope, advocate, and advance your knowledge of disability issues?
2. Given the fluctuating circumstances surrounding your family's day to day circumstances, how has completion of the *PATH* allowed you to see steps you and your child have made since your child began receiving special education services?
3. What ideas have the *PATH* provided that you can investigate in the future?

the *PATH* experience may inform parents of situations and resources that were previously unknown. Professionals can serve a significant role in answering questions and providing families with important resources that may help them move further on the self-determination path.

Sample Results

To show the differences in families and parent's level of self-determination, we selected two examples from families who have used the *PATH*. Marie is the mother of a fourth grader. Her son, Aaron, was a premature infant and has received intervention services since birth. She has experienced services in three different states and has been both satisfied and dissatisfied with the level of support. In contrast, Vanessa is the mother of a first grader. Vanessa is experiencing interactions with disability professionals in the school district for the first time. Her experience with legal issues is limited and her knowledge of disability issues is expanding, but not to the level of Marie's (See Figure 5).

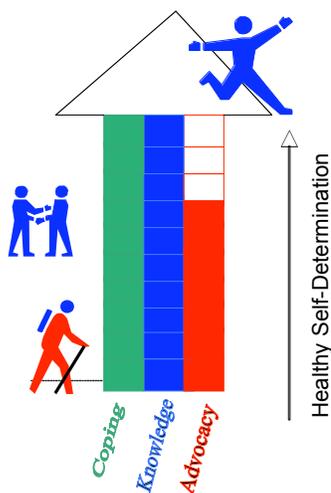
Marie and Vanessa's Reflection

The reflection section of the activities highlights differences in the mothers' development of self-determination behaviors, and both mothers' comments match their respective scores on the PATH. For example, Marie indicated, "Now that Aaron is getting older I find I need to help him become more independent in school and make sure he knows that he can ask for help and express his needs." In contrast, Vanessa focuses more on her own self-determination rather than her son's. For example, "Once you accept that your child has special needs it makes it much easier to cope."

The second reflection question focuses on self-assessment of both parent and child's progress toward self-determination since receiving special education services.

Figure 5:
Marie and Vanessa's Assessment Paths

Marie



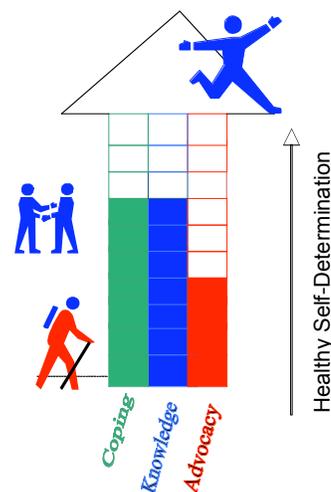
Marie, the mother with more experience notes:

We realized that Aaron is capable of so much more than we thought. We, as parents, have realized that we have many rights and can fight for those rights. We know that we have a HUGE say in what we can have for Aaron's education.

Vanessa writes:

Completion of the PATH has made me realize how much information there is out there for us to learn and I feel that my child and I have made significant improvements on knowing how to become more familiar with all of the services available to him that have allowed him and I to grow.

Vanessa



Marie's response focuses on advocacy and transferring self-determination responsibili-

ties from herself to her son. Vanessa on the other hand, is focused more on services and looking to others for support and information.

On the Assessment PATH toward Healthy Self-Determination Marie's more robust experiences is represented.

Both mothers learned there are new self-determination roles they can assume based upon their completion of the PATH activities. Both mothers were unaware of trainings to help them learn the IEP process. In addition, Marie had not considered having Aaron involved in his IEP meetings. Vanessa, the mother of a younger child, had no awareness of her own or her child's due process rights. She did not know she could veto any item on her son's IEP. Additionally, she said, "I was unaware that my legislators cared about my personal concerns about disability issues." In essence, the PATH accomplished its goal of educating and not judging or evaluating parents.

Conclusions

PATH was designed to give parents insight into their own progress and behaviors toward self-determination. The activities were designed to be informative, perhaps instructive, but never judgmental. A parent's progress on the PATH is not necessarily a forward trajectory. Life is too complicated for forward progress without setbacks. Parents will be able to take and retake the PATH activities and decide for themselves whether they are satisfied with their position, given current life circumstances within their family context.

The role of education professionals is purely facilitative. Teachers and clinicians should work with families to make the PATH available and to help them through the process the first time if needed. Facilitative language should always be used and parents should judge for themselves the value of the activities and their satisfaction with their placement on the PATH. The PATH does not require a post debriefing session. Our field testing found that debriefing often turned evaluative, thus defeating the purpose of PATH.

Another important role for education professionals in the PATH experience is to be available to answer questions and to provide resources for parents who may want to learn more about topics they discovered while completing the PATH activities. For example, Vanessa discovered she did not know she had a voice in the IEP process. This could be an opportunity to more thoroughly explain her rights and refer her to websites such as www.wrightslaw.com or to the local PTI (Parent Training and Information) center.

PATH is a tool for family learning. It is different from parent needs surveys, which are interpreted by educational professionals. Parents interpret their own PATH. As we consistently remind preservice and inservice professionals, no one knows a family better than themselves. As such, PATH belongs to families.

References

- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research, 50*, 970-976.
- Hartshorne, T. S. (2002). Mistaking courage for denial: Family resilience after the birth of a child with severe disabilities. *Journal of Individual Psychology, 58*, 263-278.
- Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special education decision making. *British Journal of Special Education, 33*, 148-157.
- Lazarus, R. S. (1998). *Fifty years of the research and theory of R. S. Lazarus: An analysis of historical and perennial issues*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Margalit, M., Raviv, A., & Ankonina, D. B. (1992). Coping and coherence among parents with disabled children. *Journal of Clinical Child Psychology, 21*, 202-209.
- Scorgie, K., & Wilgosh, L. (2007) Reflections on an uncommon journey: A follow-up study of life management of six mothers of children with diverse disabilities. *International Journal of Special Education, 23*, 103-114.
- Siegel, L. M. (2001). *The complete IEP guide: How to advocate for your special ed child* (2nd ed.). Arlington, VA: Council for Exceptional Children.
- Taber, M. (2007). Making informed decisions: Whose responsibility is it anyway? *Exceptional Parent, 37*(9), 22-23.
- Trute, B., Hiebert-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: Times of sadness and times of joy. *Journal of Intellectual & Developmental Disability, 32*, 1-9.
- Turnbull, A., Turnbull, H., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnership and trust* (5th ed.). Upper Saddle River, NJ: Pearson Education, Inc.

About the Authors:

Tammy V. Abernathy is an associate professor in the Department of Educational Specialties at the University of Nevada.

Ann Bingham is an assistant professor in the Department of Educational Specialties at the University of Nevada.