

FOP and School

Several times every year the IFOPA is asked by parents, teachers, and occupational therapists about the impact FOP has on a child's school life. The short answer is that FOP does not usually affect the person's intelligence or cognitive abilities. It does, however, negatively affect the child's ability to safely access the school premises, use and manipulate the school's materials, and function academically in a typical way. The needs of a child with FOP in a school setting have to do with gentle handling, preventing falls or bumps; and positioning the child so he/she can see, hear, and gain access to places (desk, floor) and school materials with the least amount of strain on his/her body as possible.

The various issues that arise during school can be addressed by age level: Pre-Kindergarten & Kindergarten, Elementary School (1st to 5th grades), Middle or Secondary School (6th to 12th grades) & Transition, and Post Secondary Education & Employment. As the child passes from one setting to another, many of the adaptations stay the same, some form the basis for new accommodations, and some are no longer necessary. The laws that apply to special education in public schools are the same for children from kindergarten through 12 th grade. These will be discussed in the section relating to Elementary School.

Note: This article applies to U.S. laws only, but the adaptive suggestions made in it are universal.

Pre-Kindergarten & Kindergarten

During the toddler years, children with FOP are mainly like their peers. Some may have stiffness in their upper bodies and balance problems because of the FOP toes, but in general their bodies function like their friends. This means that the primary FOP issue at this time is the overriding need to prevent trauma that may start a flareup. When preparing for Pre-Kindergarten or Kindergarten for a child with FOP, most parents have found that the best way to be sure everyone understands all the concerns is with a face-to-face meeting where the best interests of the child is clearly the focus. Such a meeting should include everyone involved with the educational experience of the child, including the new teachers, previous teachers, aides (if any), school nurse, and any service providers, such as Occupational Therapists (OTs), Physical Therapists (PTs), speech & language specialists, etc.

The decisions reached during this meeting should be written down to make it easy to bring other participants up to date and to encourage compliance. It can be done informally, or the plan can be part of a formal "Individualized Education Plan (IEP)" (pursuant to the Individual with Disability Education Act (IDEA)) or part of a written "504 Plan" (pursuant to the Rehabilitation Act of 1973). See below for more details. This meeting should take place *before* school starts to assure that the child's inclusion will be seamless and natural. In general, the more you do before school starts, the better it will be for the child.

Over the past several years, many FOP parents have written to each other regarding various daily management issues of FOP as it relates to pre-K & kindergarten. These concerns, and how they were managed, are listed below:

1. **One-to-One Aide:** The parent must decide whether to request a one-to-one aide for the child with FOP. The aide's primary focus at this age would be to try to keep the child from sustaining trauma by watching for hazards of all kinds, such as slippery surfaces, tripping dangers, and other very young children (often with poor impulse control). In addition, the aide would provide focused supervision during the commotion of the cafeteria and playground. Whether an aide is the best way to keep the child safe will depend on the size of the class, the facilities & layout of the school, and the child's degree of FOP stiffness. Dr. Kaplan has written letters to schools explaining the need for an aide's protection;
2. **Tables and Desks:** Tables and desks should be at the right height for minimizing the strain on the child's neck and back while playing and drawing. Since many children with FOP have trouble sitting on the floor to play or work, some other appropriately sized surface should be available for him or her to use. To encourage socialization, the surface should also be big enough for several children at once. Occupational Therapists (OTs) could work on this issue with you and/or the school;
3. **Writing Aides:** To facilitate early writing skills, a slanted desk top or writing board (which can be made by taping two binders together) can help a child with restricted neck movement learn to write with less strain;
4. **Cubbies:** To foster independence, the coat hook of a child with FOP can be lowered to a height that the child can manage on his or her own. To reduce the dangers of crowds, the cubby itself should be in an area less prone to the traffic of children all going to their cubbies at the same time;
5. **Rugs and edges:** All area rugs must be taped down and checked for edges that might trip the child. Corners of cabinets and shelves can be padded with pre-made padding sold for baby proofing a house;
6. **Inspection:** The parent can request the right to inspect the classroom for safety hazards, such as narrow or cluttered passageways, books on the floor, etc both at the beginning of the school year and periodically throughout it;
7. **Publicize Safety Rules:** It is important that the other children in the class be aware of the special FOP related safety rules. Either the teacher or the parent may speak to the children in age appropriate language, telling them a little about FOP and reminding them to always push chairs in close to the table, hang up coats so no one trips on them, not push on the way to the door, etc;
8. **Staff Meetings:** To spread correct information about FOP and the child's needs, the parent might meet with not only the child's teachers and therapists, but also ancillary school personnel, such as lunchroom staff, maintenance people, & other teachers;
9. **Safety meeting:** Parent should discuss with the school how to care for the child with FOP during fire drills, real fires, and other emergencies, such as choking incidents;
10. **"Sensitivity meeting:"** Educating everyone about FOP - students, parents, everyone - may minimize teasing and bullying later. A sensitivity meeting can be as simple as a meeting of classmates and staff, a general assembly, or anything in between. It can be a real opportunity for educating the school about FOP and the issues of living with a chronic illness;
11. **Communication:** Some parents have written letters to the parents of all the children in the same grade as the child with FOP explaining FOP and how it is affecting their child. This is one way to be sure that other parents have accurate information about FOP, and not just second-hand

stories from the kids. Since you opened the door to communication with a letter, it can make it much easier for other parents to talk with you about your child & FOP. This models the kind of open communication and sensitivity that you want the children to copy, as opposed to teasing and staring;

12. **Seating:** The chair of a child with FOP must be very stable, possibly padded, and at the right height so that the child's feet are always firmly planted on the floor for proper back alignment. Depending on the position of the child's elbows, the chair may need to be armless. As the child gets older, his or her chair may need to swivel;
13. **Emergency Information:** The IFOPA's FOP emergency & tissue collection cards should be kept in the classroom along with a one page Emergency Instruction sheet with specific care information and the contact information of those to call in case of an emergency, such as Mom, Dad, pediatrician, etc;
14. **"Pick Me Stick:"** As a substitute for raising one's hand, many parents create a "pick me stick," an item on a stick about an arm long to be waved to get a teacher's attention.;
15. **Floor sitting:** Circle or rug time may be difficult if the child can't sit on the floor unsupported. A stand-alone booster seat, floor chair, big pillow or bean bag may help the child stay at the same level as his or her peers;
16. **Recess and Playground:** Recess and playground time can be difficult for many children for a lot of reasons. For a child with FOP, and the adults around him or her, the safety factor is the biggest issue and the resulting stress can be significant. If there is a one-to-one aide, he or she should stay close to the child with FOP and try to watch the area around the child for any dangers, such as tripping hazards, running children, or trees. It is important to try to find ways for the child with FOP to be part of the child-initiated group activities despite the presence of an adult. This gets harder as kids get older because they begin to make up their own games and most of them involve running, climbing, chasing, wrestling and other things the child with FOP might not be able to do safely. To help involve other children in what the child with FOP is doing, the parent or teacher can bring in special materials or equipment that everyone can use during recess, such as sand toys, long-handled shovels for sand boxes, large pieces of chalk to be used for coloring or tick tack toe on a wall or ground, colorful soft balls for kicking, catch, etc. The idea is to create games that will be fun, safe, and engaging to several kids, not just the child with FOP. A note about playground sand: Foreign objects should be removed from school sand on a regular basis to prevent the child with FOP from banging against things while playing in the sand or tripping over things while walking through it;
17. **Assistive Technology (AT) Evaluation:** Assistive technology is any item that helps a person with a disability perform a task. It includes low tech items, like pencil grips, and high tech items, like special computer keyboards. The proper time for an AT evaluation is determined by the child's physical limitations and educational difficulties, & by the recommendations of the child's teachers, parents & therapists.

Elementary School (1st through 5th Grades)

There are several laws that support the provision of special services for children with disabilities and they apply throughout the school experience, from kindergarten to graduation & transition. The most cited law is the **Individuals with Disabilities Education Act (IDEA)**, the federal law that requires public schools to make available to all eligible children with disabilities a free appropriate public education (FAPE) in the least restrictive environment (LRE) appropriate to his

or her individual needs. If children are found to be in need of special education services under this law, they receive an Individualized Education Plan, or IEP.

The second law which supports the inclusion of children with special needs is **Section 504** of the Rehabilitation Act of 1973, the federal law that prohibits discrimination on the basis of disability in institutions receiving Federal funds, such as schools. This law requires a "level playing field" for all students, including those with disabilities. Children receiving services under this law receive a written "504 Plan". For more information on these laws and various other issues of educating a child with special needs, please see www.wrightslaw.com, an invaluable website that provides easily understandable information for parents about education, special education, advocacy and the successful management of the education bureaucracy.

Which of these laws best applies to the situation of any given child with FOP depends on several factors, including physical symptoms, academic performance, and the standards of the state in which the child lives. The school district may classify a student with FOP as in need of Special Education assistance under the IDEA because FOP is causing an "educational impairment" that only a complex assortment of services can accommodate, such as full-time aide, Physical & Occupational Therapy, Assistive Technology services, and/or door-to-door transportation. On the other hand, some school districts refuse to classify a child with FOP this way unless the child is performing below grade level, i.e. exhibiting an "academic" impairment.

In order to secure the necessary accommodations in the most efficient way, it is very important for the parents to get to know the people involved in the special education and disability field in their school district. The parent can seek advice from the teachers, principal, Special Education PTA representative in the school (if there is one), special education liaison at the school (such as the resource room teacher), and parents of other children with disabilities. Of course, it helps to know the state and Federal laws backing up your request for services and accommodations. The Wrightslaw website mentioned above (www.wrightslaw.com) has a state by state "yellow pages" that will give local sources that may be able to advise you. *Exceptional Parent Magazine*, another great resource for parents of school age children with special needs and/or chronic illnesses, also has an excellent state by state resource guide. Please see www.EParent.com for more information. Whatever the parent's level of special education knowledge, tact, mutual respect, and a desire to educate about FOP will go long way towards getting the child whatever he or she needs to succeed at school.

In addition to the issues discussed above regarding kindergarten, several additional concerns need to be considered during the elementary and middle school years when the child learns to read and write in earnest:

1. **One-to-One Aide:** For a child in this age range, the aide not only looks for hazards, but also assists the child in the lunchroom and bathroom (if needed), carries books, puts materials in front of the child (if needed), copies assignments and scribes other work when appropriate to limit arm fatigue, and assures safety during transitions around the school;
2. **Writing:** A slanted desk top or writing board, whether purchased by the school or made by taping two binders together, will ease the stress writing puts on the child neck and back. An adjustable desk top that can be set at different angles can serve the multiple purposes of a

writing board and a book holder. Please see [What is FOP Guidebook](#) Chapter 6 of *Overcoming Obstacles* for a collection of alternative solutions to this problem;

3. **Desk:** A desk that can be adjusted to different heights will be able to accommodate the varying degrees of back flexibility exhibited by a child with FOP over the course of a year or several years. A "wheelchair cut out" design that is curved to allow a wheelchair to get very close to the desk can give the child with FOP the maximum space he/she can access with limited arm movement. An L-shaped, two desk set-up can also maximize the amount of space accessible to the child with FOP;
4. **Paper holder:** To ease the strain of trying to read from a single piece of paper, or copy from one, a copy or page holder can be extremely helpful, such as a "PageUp" from Staples or other office supply store;
5. **Book holders:** For a child who cannot tilt his or her head down to look at a book resting on the tabletop, a book holder is essential. Please see [What is FOP Guidebook](#) Chapter 5 of *Overcoming Obstacles* for a collection of various book holders;
6. **Velcro holders:** School materials, such as pens, papers, etc can be kept within reach of the child with FOP by holders fastened by Velcro. The occupational therapist should be able to create the necessary aides;
7. **Chair:** A height adjustable swivel chair (preferably padded) can compensate for a head and body that doesn't turn. It also makes it much easier for the child to stay focused on the teacher and follow the action in the classroom;
8. **Foot rest:** A foot rest can help the child maintain proper leg to hip position and thus reduce the strain on his or her back and spine while sitting. This is also something that the occupational therapist should teach the aide and/or teacher to check on a regular basis;
9. **Priority seating:** Since some students with FOP often cannot turn their heads due to neck stiffness, they should be seated where they can see the teacher easily and without strain. Also, seating the student in the front of the classroom can also accommodate the moderate hearing loss often associated with FOP;
10. **Backpacks:** To reduce the strain on the child's back, a rolling backpack can be very helpful, as can having a 2nd set of textbooks at home and/or an aide to carry things;
11. **Transportation:** If the child with FOP will be taking a bus, the bus aide should be educated about FOP, understand the need for safety and seat belts, and given an opportunity to ask questions. Many children who have FOP receive door-to-door transportation, as opposed to being picked up at a bus stop, which would involve the risks of a walk and wait;
12. **Physical Education:** During this period, the activities in PE will vary from simple safe activities, like games & exercises, to more active and/or risky activities, like gymnastics & soccer. These activities may be modified on an as needed basis for the child with FOP and his/her aide. Or, the student might be excused from physical education, attend adaptive P.E. (a program created just for him or her), or receive time with a Physical Therapist. One school district arranged for the child with FOP to get her PE credits in a special swim class that helped her physical development in many ways;
13. **Safe Games:** The parent should be part of the creation of appropriate recess and PE activities. Soft balls, long tools, and other appropriate equipment & games can be brought in for these times;
14. **Test and Work Modifications:** The child with FOP may need extra time for tests and assignments that require a lot of writing. If so, it needs to be written into the Individualized Education Plan or formal 504 plan;
15. **OT and PT evaluations:** OT and PT evaluations of the child's hand and arm strength, fine motor skills, balance, ability to transition from floor to feet, ability to toilet independently, etc., can be

very helpful. As needed, the therapists can work on these skills, maintain current muscle strength and flexibility, and compensate for increasing stiffness as long as they appreciate how it needs to be done without straining the child's body;

16. **Independence:** The school can assist in the creation of activities that will allow the child with FOP to develop his or her growing sense of independence and self-confidence, especially at school. For example, carrying messages to other teachers during times when the halls are quiet, helping younger children at lunch, policing an area for litter, etc;
17. **Afterschool Activities:** The child with FOP should be able to attend appropriate afterschool activities, if they are being offered to the rest of the students. The school district may have to pay for the aide to attend these activities as well. This may depend on the child's educational classification and on the level of advocacy by the parent;
18. **Assistive Technology (AT) Evaluation:** As the work load increases with each passing grade, so does the responsibility of the school. A good AT evaluator will be able to suggest time- and energy-saving electronic devices and software to help the child with FOP keep up with peers and conserve energy and arm strength. Some examples of AT are computers with accessibility software and hardware.

Secondary School (6th to 12th grades) & Transition

The work load at this level of school often overwhelms the strongest of students. Reading, writing, researching, thinking, and extra-curricular activities all come into the picture. To help the student with FOP succeed, the previous adaptations should be re-evaluated to see if they are the best and most up-to-date options available. There may also be a few new concerns to be considered, such as the transition to the post-high school life of college and/or employment:

1. **One-to-One Aide:** For a student in this age range, the aide's duties expand. She or he may assist the student with lunch and toileting (if needed), carrying books between classrooms, setting up complicated materials (test tubes, etc), taking notes and copying assignments, scribing other work when appropriate, and helping the student with transitions around the school so that they are safe & timely. The child and aide may need to leave each class 5 minutes early to avoid crowds of students in the hall;
2. **Assistive Technology Evaluation:** At the same time that school work increases dramatically, FOP may be limiting the student's mobility. AT may now include mobility equipment such as wheelchair, scooter and cane, and more electronic technology, such as a laptop computer, accessibility software and hardware.
3. **Test and Work Modifications:** There may now be a need for further test and assignment modifications, such as oral test-taking, extra time, less homework, submitting work written on the Palm Pilot (which means it would have to be brought home, downloaded, printed & returned to the school for submission). As always, these accommodations will need to be written into the child's Individualized Education Plan or 504 Plan;
4. **Transition:** Public schools must address the transition to post-school life for students who have an Individual Educational Plan (IEP or IPE). Transition services begin when the student is age 14. The student and his/her family decide on the student's goals for the future. School and community personnel work with the student and parents during the last years of public school to prepare the student for life after graduation. Vocational Rehabilitation becomes involved with transition services during the last year of high school. The transition services required by a 504 Plan are not as well described.

Post Secondary Education & Employment

"Post-Secondary Education" is education after High School, such as University, Community College, Technical or Vocational Training. Now that the student with FOP has graduated high school, there are several new issues to be addressed and resources to be accessed:

1. **Department of Vocational Rehabilitation or DVR or VR:** Vocational Rehabilitation is a program of the U.S. federal government. It is administered by each state. VR's mission is to enable individuals with disabilities to obtain and keep employment. If you qualify, which is based on degree of disability and financial need, VR can pay for tuition and books, assistive technology (such as the most current and comprehensive computer hardware and software), mobility devices, transportation, hearing aids, attendant hours, and more to help you get training for the kind of work you want to do. You can find contact information in the telephone book under "State" or search for "Vocational Rehabilitation + (your state)" on the Internet.
2. **Disabled Student Services Office or DSS:** Every college and university that accepts federal dollars (nearly all schools) has a DSS Office that works to ensure that students with documented disabilities receive the accommodations they need. Unlike public school where it is the responsibility of the school district to assess students and provide services, at the post-secondary level, it is the student's responsibility to disclose the disability and ask for the accommodations he/she needs. Accommodations might include: note-taker, lab assistant, group lab assignments; classrooms moved to an accessible location; extra exam time; scanning services; computer with special assistive technology such as on-screen keyboard, voice input, trackball mouse, and textbooks on CD.
3. **Legal Rights :** According to Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, "no otherwise *qualified** individual with a disability shall, solely by reason of his/her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity of a public entity." These are the rights of everyone with a disability, including FOP, everywhere in society. *In post-secondary education, the word "qualified" means "a person who meets the academic and technical standards requisite to admission or participation in the education program or activity, with or without reasonable modifications of rules, policies or practices; the removal of architectural, communication or transportation barriers; or the provision of auxiliary aides and services."
4. **Supplemental Security Income (SSI):** SSI is a needs-based program that pays a monthly income to people with disabilities. Family income and assets are considered in determining whether a child qualifies for SSI. At age 18, a person may have up to \$2000 in assets and still qualify for SSI. Persons who receive SSI benefits also qualify for Medicaid Health Insurance and attendant care. The Social Security has other programs you may qualify for, including Social Security Survivors Benefits and Social Security Disability Benefits. For more information, please see www.ssa.gov
5. **DO-IT:** DO-IT stands for Disabilities, Opportunities, Internetworking and Technology. DO-IT is a science and technology program at the University of Washington in Seattle. Its mission is to increase the participation of individuals with disabilities in challenging academic programs and careers. For those outside Washington State, DO-IT Pals is an online community of teenagers with disabilities who communicate by email with DO-IT staff, mentors, and one another. DO-IT Careers supports opportunities for students to participate in work-based learning experiences. DO-IT staff helps students with resume preparation, job search strategies and networking. See <http://www.washington.edu/doiit/>

SAT Test Accommodations

The Scholastic Aptitude Test (SAT) offered by Collegeboard.com is a standardized test taken by high school juniors and seniors. The score is submitted to colleges as a way to compare students in the graduating class nationwide. The Preliminary Scholastic Aptitude Test (PSAT) is a "practice" SAT taken in the fall of junior year. PSAT scores are used to nominate National Merit Scholars.

Accommodations for the PSAT and SAT can be made for students with a disability. The College Board grants the accommodation. Your high school counselor is the person to negotiate accommodations for you with the College Board. The accommodations documented in your Individual Educational Plan can be presented to the College Board. If you need accommodations that are not in your IEP, you can provide a doctor's letter explaining why you need the accommodations and your counselor can submit it.

We are aware of the following accommodations being provided to students who have FOP: extended time, such as "time and a half," which is 50% more than the time usually allowed to students for the test (for example, 90 minutes for a 60 minutes test); a scribe to record answers; being allowed to move around during the test when needed to release physical stiffness; alternative test location to facilitate access or special seating, such as taking the SAT in the counselors office; and divided seating, to accommodate a student who cannot tolerate taking the SAT in a single 4½ hour session, which is the standard time and a half accommodation for a 3 hour test, and therefore he or she takes the divided test in two sessions, 2¼ hours each, preferably on two consecutive days.

Scholarships

Scholarships are gifts and awards based on a student's academic achievement, background, or other criteria. Disability-specific scholarships are quite limited, so students with FOP are encouraged to also pursue scholarships available for criteria other than disability.

Financial Aid Information

<http://www.ed.gov/>

<http://www.collegeboard.com/>

General Scholarship Lists

<http://www.internationalscholarships.com/>

<http://www.fastweb.com/>

http://apps.collegeboard.com/cbsearch_ss/scholarshipSearch.jsp

<http://www.scholarship-page.com/>

<http://www.free-4u.com/>