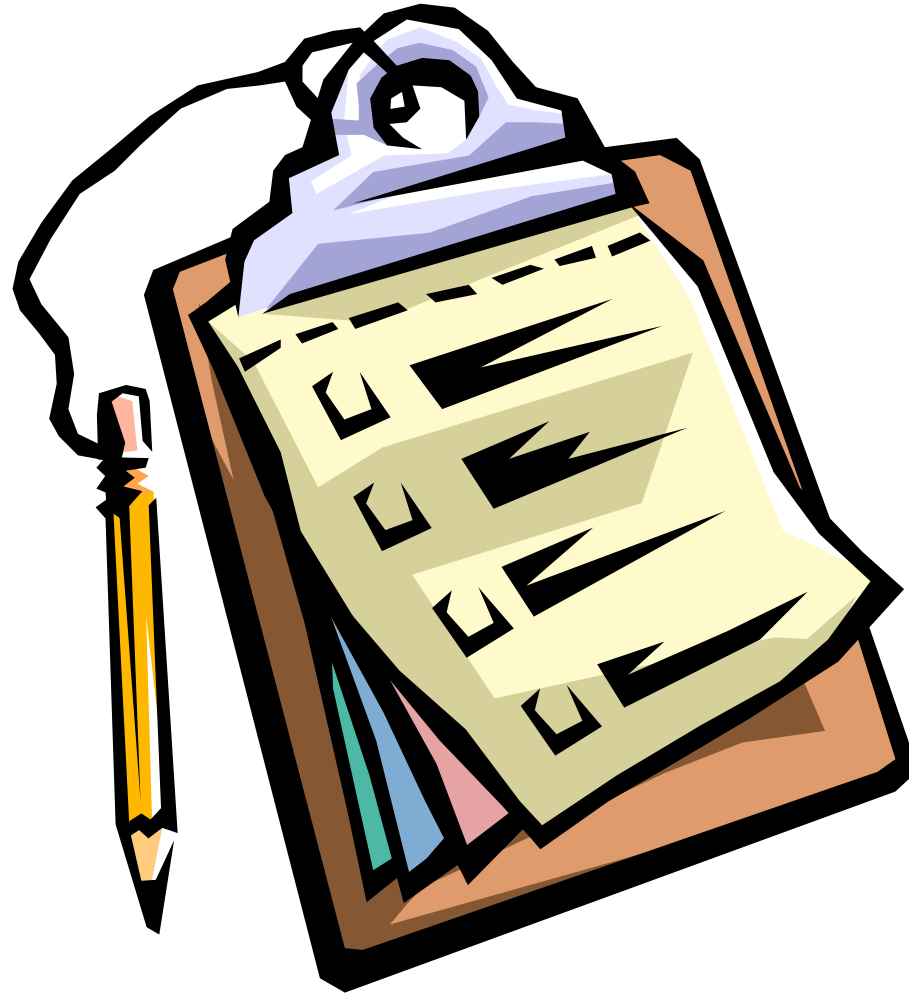


Transition to Adulthood Checklist



A Publication of Batten Disease Support and Research Association

Introduction

You are receiving this book because your child will be turning eighteen within the next twelve months. There are many issues that children over age 18 with Batten Disease face that other Batten children do not. This guide and checklist is designed to help you prepare adequately for what lies ahead. Some of the topics in this guide can take a substantial amount of time to inquire about and establish. Your child may already be receiving some of the items in this list. If this is the case, you will want to contact the specific program or service to see if anything changes once your child turns eighteen. While many of the things on this list cannot be tackled until your child turns eighteen, this guide will help you to prepare.

Organization is the key when it comes to these issues. If you have not already begun a file or folder for your child's programs and benefits, now is the time. Many of the items in this list require attention and detail on a monthly basis. You'll want to have everything in one place in case you need an item at a moment's notice. It is also important to begin keeping written records of all correspondence for your child's benefits. These records allow you to keep a detailed paper trail when it comes to your child. It is good idea to keep photocopies of your child's doctor's records and other medical information. Remember, never send or give original paperwork to anyone. Make photocopies if needed for providers, applications and others. Let this checklist be a guide or tool in your process of organization.

Many of the terms listed in this document may be different from how your state refers to them. Every state has a department that handles things like Medicaid, services for the developmentally disabled or mentally retarded population, etc. If you have not already, you will want to familiarize yourself with these departments and the terms they commonly use. I welcome any additions or changes you would add to this publication. As always, if you have questions about anything, please contact me.

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Apply for Supplemental Security Income (SSI) and/or Social Security Disability (SSDI) benefits

It's important to know that your child can receive both SSI and SSDI benefits. SSI benefits are determined based on income and disability. You must be able to prove that your child does not receive more than \$940 in income every month. SSDI benefits are available to a child who was disabled before age 22. These benefits are based on the parent's work history and payment into the Social Security system during their career. At least one parent must be receiving disability or retirement benefits currently or be deceased in order for a child to qualify for SSDI payments. You can schedule an appointment for Social Security starting the first day of the month following your child's birthday. So if your child was born on March 15, you can schedule an appointment with Social Security for April 1. Please review the Medicaid FAQ booklet that came with this checklist for more information or visit the Social Security Administration website at www.ssa.gov.

STEPS TO TAKE	DATES AND NOTES
Visit Social Security website: www.ssa.gov	
Call local SSA office to schedule an appointment (can do this for the first day of the month following your child's birthday)	
Make sure child has little to no assets in his/her name	
Have proof of disability before age 18 (SSI) /age 22 (SSDI)	
Make sure to let the Social Security worker know that your child has a terminal illness (expedited process)	
Inquire about Presumptive Disability Payments for your child (payments your child can receive up to 6 months while waiting for a decision)	
Complete necessary paperwork and return	
Appoint yourself as Payee for your child (responsible for all income and expenditures)	
Receive first SSI/SSDI payment	
Additional Notes:	

If SSI/SSDI is denied, apply for Medicaid Insurance

If your child is approved for SSI, **Medicaid** insurance is also approved. You will want to check with your local Social Security office to inquire if Medicaid paperwork needs to be completed. If your child receives SSDI, he/she will be eligible for **Medicare** two years after the SSDI benefits are approved. However, if your child fails to qualify for Social Security benefits, apply for Medicaid for your child. Medicaid is an income-based insurance program. Your child cannot have too many assets in his/her name in order to qualify. It is possible that your child may have too many assets for Social Security but not too many to receive **Medicaid** insurance. The income limits vary from state to state. You may be able to keep your child under your private insurance and receive Medicaid as a secondary insurance. Check with your local Medicaid office for more information, refer to the Medicaid FAQ booklet sent with this checklist, or visit the Federal Medicaid/Medicare Center website at www.cms.gov.

STEPS TO TAKE	DATES AND NOTES
Call your private insurance company to inquire about children over age 18 who have disabilities	
Call or visit local/county Department of Social Services office (department that handles Medicaid and Medicare for each county or region)	
Have proof of disability before age 18 (diagnosis, doctor's records, school records, etc)	
Make sure child has little to no assets in his/her name	
Collect any proof of income for your child	
Complete necessary paperwork and return	
Receive Medicaid Benefit card	
Learn about coverage for your child w/ Medicaid as primary or secondary insurance	
Additional Notes:	

Inquire about state or county's process for Guardianship/Conservatorship

Guardianship/Conservatorship can be a lengthy and confusing process. Obtaining guardianship/conservatorship as soon as your child turns eighteen is important for many different reasons, one of them being the power to make medical and financial decisions for your child legally and without questions. There are different steps you can take to prepare yourself. If you have a simple family system (mother and father are still married and child lives in the home) the process should be relatively easy and hassle-free. As a family situation becomes more complex (child has a different father or mother; grandmother is legal guardian; etc) the process of Guardianship may take a little longer. You may or may not need an attorney. This is a personal decision. Call your local county Probate Court (the court that usually handles Guardianship hearings) to see if they can provide an attorney or recommend an attorney in your area. Depending on the paperwork and court-provided assistance, many families choose to complete the process without an attorney. The Probate Court may have a specific person designated to help families with the Guardianship/Conservatorship process. Different community or state agencies may also provide funding for Guardianship cases. Fees for obtaining Guardianship can vary depending on the complexity of the case. Contacting state disability advocacy organizations about financial assistance may help lessen the burden on your family. Your child will receive an attorney. This attorney is looking out for the best interest of the child and will most likely agree with your pursuance of Guardianship. This attorney is court-appointed and you will not have to pay for them. Visit the National Guardianship Association at www.guardianship.org for more information.

STEPS TO TAKE	DATES AND NOTES
Contact county Probate Court or Family Court	
Locate and contact state guardianship organization	
Contact state or local advocacy groups for financial assistance (ARC, Department of Developmental Disabilities, state guardianship association, etc)	
Assess need for attorney and make appropriate contact	
Fill out necessary paperwork and submit to court	
Additional Notes:	

Child's Educational Needs

Reaching adulthood is also a transitional time for children in the education system. The U.S. Department of Education and the Federal *Individuals with Disabilities Education Act* (IDEA) set up for students with disabilities, states that a child can receive school services through age twenty-one. However, each state has some say in the age at which services can stop. Most parents choose to keep their child in the educational system past their eighteenth birthday. The school system can provide your child with socialization opportunities and other benefits like physical or occupational therapy that may be hard to find in another setting. Depending on your child's school system, they may be able to participate in the graduation ceremony but would receive a "certificate of attendance" rather than a high school diploma. As long as your child receives a "certificate of attendance" rather than a high school diploma, he/she can still receive special education services. Make sure to have a conversation with your child's IEP team about a "transitional" plan for your child. They should also be able to give you information on services available to your child after they become too old for services through the Dept. of Education.

STEPS TO TAKE	DATES AND NOTES
Will your child leave school at age 18?	
Does your child still enjoy school or has it become stressful?	
Inquire about different day programs (i.e. half-day; work-related; living skills; etc)	
Would your child benefit from a work/vocational program?	
Will there be a change in transportation?	
What transitional programs are available?	
Does your child currently receive any therapies at school and would you like these to continue?	
Additional Notes:	

Child's Current Medical Needs

Making plans for your child's medical needs is just as important as Social Security or Medicaid. Some issues are time-sensitive like the cut-off age for your child's current Medicaid Waiver (if they have one). Other issues, like finding an adult neurologist compared to your child's pediatric neurologist can be a more gentle transition. These issues are things you can look at and consider over time. These do not need to be hasty decisions, but rather a topic of conversation over the next few years.

STEPS TO TAKE	DATES AND NOTES
Is your child currently on a waiver that expires at age 18 or 22?	
Is there a better waiver available for individuals over 18?	
Inquire about the different waivers available	
Assess your child's long-term medical needs	
Is your child eligible for new programs through a different agency or organization?	
Assess your child's long-term equipment needs	
Can your child receive new funding guidelines for equipment or care?	
Can your child continue seeing a pediatric neurologist?	
Can your child continue seeing their pediatrician?	
Do your current doctors accept Medicaid?	
How long can your child remain on your private insurance?	
Will there be a switch in medication names with Medicaid? (i.e. name-brand vs. generic prescriptions)	
Additional Notes:	

Your Child's Financial Future

Having your child's finances in check are important for things like Social Security or Medicaid. Children with disabilities can only keep very limited assets in their name, less than \$2,000 in most cases. It is also hard for parents to give up financial control and begin paying for their child's expenses out of the child's account. Parents are used to paying for all of their child's expenses up to this point. You may also want to look into setting up a Special Needs Trust for your child. This allows parents and other individuals to set up their will and be able to leave money and assets to a child with disabilities without the assets affecting the child's eligibility for benefits. Money in a Special Needs Trust is to be used for anything that isn't considered a basic need like food, clothing, or shelter. You'll want to find a lawyer in your area with experience in establishing Special Needs Trusts. For other questions or issues about finances, consult with your financial planner or consultant. Visit the Academy of Special Needs Planners website at www.specialneedsanswers.com for more information.

STEPS TO TAKE	DATES AND NOTES
Does your child have a checking or savings account?	
Are you using this checking account for all of your child's purchases?	
Learn about the income limitations and time-sensitive financial matters for Social Security and Medicaid (i.e. how long can you keep money; what is the largest amount of money my child can have in their name at any time; etc)	
Keep track of your child's monthly expenses (food, rent, personal items)	
Do you have a will set up for you and your spouse? Is your child listed in that will?	
Are there things you would like to leave to your child in the event of your death?	
Talk with your attorney about setting up a Special Needs Trust	
Consider hiring an attorney with experience in Special Needs Trusts	
Appoint a trustee to oversee the Special Needs Trust	
Talk about your wishes with your closest family and friends	
Additional Notes:	

Additional Notes

PROGRAM OR SERVICE NOTES	DATES