Transitions of Care

For Children with Medical Complexity and their families

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DELAWARE HEALTH AND SOCIAL SERVICES

Delaware Division of Medicaid & Medical Assistance

Transitions of Care

Transitions of Care are moments when a child's care is transferred from one setting or level of care to another. These transitions are particularly vulnerable points in the child and family's journey within the healthcare continuum.

This toolkit is intended to serve as a guide supporting families within Delaware to anticipate and plan for such changes.

Click on the button to learn more about the type of Transition of Care that you are having.

Facility to Home

Child to Adult

Change Provider

Other

Facility to Home

- Coordinating the Return Home
- Insurance Coverage
- What to Expect Before You Come Home

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Facility to Home

Coordinating the Return Home

- ❑ Request support from a Care Coordinator with your Managed Care Organization (MCO).
- ❑ Contact an institutional discharge planner and a MCO care coordinator about discharge date and verify where child will be discharged to.
- ❑ Request and review a list of needed services and supplies to safely leave the institution. This includes support with housing, food, and scheduled transportation if needed.
- ❑ Request a home and environmental assessment if one has not been offered, so that equipment ordered can be used in your home and to determine whether it can be transported in your vehicle or will require special delivery.
- ❑ Choose community providers and pharmacy for services, supplies, and equipment including start date of services and first date of delivery for supplies. Verify if medications will be delivered or if they must be picked up at the pharmacy.

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Facility to Home

Coordinating the Return Home (continued)

- Obtain contact names and numbers for all providers and suppliers.
- Make sure that all aftercare appointments for physical health are within 14 days of discharge and for behavioral health are within 7 days of discharge.
- Verify that the community primary care physician is aware of all discharge orders.
- Communicate anticipated discharge date with the child's school.
  - Discuss service needs with school counselor/nurse and whether equipment will be needed at school.
  - Support communication between the facility discharger planner and school counselor.
  - Make needed amendments to the Individual Education Plan (IEP).
- If your child is supported by the justice system; you may also be assigned a Youth Case Manager to help with transitions from facility to home/foster home.

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Facility to Home

Insurance Coverage

- Ask the hospital care coordination team about what insurance covers and anticipated co-payments for all services, pharmacy, supplies, and equipment needed for discharge.
- Share the anticipated costs for discharge and coverage with the MCO Medicaid Care Coordinator.
- If your child is a newborn, coordinate a Medicaid application with the hospital social work/nursing staff.
- If discharge is to a facility-based care (Nursing facility, Intermediate Care Facility), apply for Long-Term Care Medicaid.

Referrals

- Apply for Supplemental Security Income (SSI)
- Complete referral to Delaware's Division of Developmental Disabilities Services (DDDS)

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Facility to Home

What to Expect Before You Come Home

- You will be asked to complete assessments to evaluate your needs after you leave the hospital.
- Expect after discharge follow-up visits.
  - Depending on your needs and where you will be living after discharge, you may have multiple aftercare visits or phone calls to check on you.
- Your case manager/care coordinator will ask you to help develop your child's plan of care and a transition of care plan.
- If you receive personal care or Self-Directed Attendant Care and/or other home health services, you will be asked to verify the services you receive using a system called Electronic Visit Verification (EVV).
- Gathering documentation for Letters of Medical Necessity, Level of Care, and service authorizations.

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Child to Adult Services

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Child to Adult Services

What to Expect and Tools to Help

- Check the currency of all insurance coverage. When will your private insurance coverage end?
  - For most private insurance, families can cover their adult children until their 26th birthday.
  - For Medicaid, pediatric coverage ends on the child's 18th birthday.
- Transition of Care planning meetings with Nemours starts at age 14.
  - There is a special transition team to support you.
- Transition of care planning meetings with the school also starts at age 14.
  - There will be a section of your child's IEP that specifically addresses transition needs.
- Contact your MCO Care Coordinator at least one year prior to the child's 18th birthday.
  - Determine when to apply for adult Medicaid and what documentation will be required.
- Review your list of current providers and determine if change from pediatric to adult providers is needed.

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Child to Adult Services

What to Expect and Tools to Help (continued)

- Make an appointment with the MCO Care Coordinator to review all services that your child currently receives.
  - This includes everything from face-to-face services, medication, diapers, formula, and so on.
- Ask the care coordinator to explain how coverage and benefits may change when transitioning to adult coverage.
- Ask about Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) coverage from age 18–21st birthday.
- Ask about adult day programs, Home- and Community-Based Services (HCBS) waivers (including Pathways to Employment), post-secondary education options to determine how to best support your child when school ends.
- Schedule tours of programs so that you can make informed decisions.
  - Start this process as early as the 16th birthday to allow enough time to see as many options as possible.
  - Include your child's school IEP team in your decisions about what you are planning after school.

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Child to Adult Services

Things to Do and Tools to Help

- Apply for SSI if you have not already done so.
  - Talk as a family about how you will consider this income.
  - What will you report to SSI for rent and living expenses for your adult child?
- Contact the Parent Information Center (PIC) available at https://picofdel.org/ for additional support with transition to adult services.
- Contact Delaware Community Legal Aid Society to help you learn about and evaluate guardianship and supported decision making options.
  - The Guardianship and Alternatives to Guardianship for Adults with Disabilities Brochure is available at https://www.declasi.org/wp-content/uploads/2014/03/Guardianship-and-Alternatives-Brochure-March-2014.pdf
- Apply for guardianship and review and amend your will to include any changes so that all legal decision-making documents align/agree.
  - Begin this process well before your child's 18th birthday to ensure that you have an authorized decision maker in place before your child turns 18 years old. The Supported Decision-Making Summary is available through Delaware Health and Social Services (DHSS) at https://dhss.delaware.gov/wp-content/uploads/sites/2/dsaapd/pdf/supported_decision_making_information.pdf
- Other helpful tools:
  - gottransition.org/resource/?pediatric-vs-adult-care-differences

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Changing Providers

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Changing Providers

- Notify all care coordinators helping with your child's care when you are expecting a change in providers.
  - This can happen when you are ending services or starting services.
- You have a right to review and decide what information is shared among the providers on your care team.
- Update your child's current plan of care to ensure all provider relationships and contact information is current/accurate.
- Rescind consent to exchange/release information with providers if needed.

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Other Things to Keep in Mind

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Other Things to Keep in Mind

- Develop a care notebook that contains all providers, contacts, plans of care, mail/notices about your child's care so that it is all in one place.
  - PIC can help connect you with resources on how to build a care notebook.
- Ensuring that insurance contact information is current and accurate.
- Report changes in any insurance coverage that you have to your case manager/care coordinator.
- Report changes in decision makers, and/or guardianship.
- Report changes in advanced directives.
  - Provide copies to all providers
- Accurately and thoroughly describing your needs in assessment interviews including needs for things like support with housing, food, and transportation.

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Other Things to Keep in Mind (continued)

- Choosing how you prefer to be contacted.
  - Make sure numbers, emails, and addresses are all kept current.
- Choosing providers.
- Signing consent to release/share information among healthcare providers
- Signing consent to release/share information between healthcare providers, the health plan and your child's school.
- Evaluating your capacity to provide care while also working, taking care of other children and yourself.
- In addition to your care coordinator and care providers, you may want to consider family support or caregiver support groups near you to become involved with.

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