

New Diagnosis

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Less than 3 years:

- early intervention services through Case management Agency in your county
- apply for medicaid waiver based on eligibility
- insurance based therapies
- establish care with pediatric primary caregiver
- developmental pediatrician or child psychiatrist for behavioral medication management and guidance to primary care giver
- other specialists according to diagnoses through Children's Hospital Colorado or Rocky Mountain Children's Hospital

Greater than 3 years:

- residential school district for enrollment and IEP/504 plan consideration
- apply for medicaid waiver based on eligibility
- insurance based therapies
- establish care with pediatric primary caregiver
- developmental pediatrician or child psychiatrist for behavioral medication management and guidance to primary care giver
- other specialists according to diagnoses through Children's Hospital Colorado or Rocky Mountain Children's Hospital

Pediatric to Adult Transition

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- start talking to pediatrician before your child turns 18 so you and they have time to prepare for transition**
- ask for list of preferred adult providers who work with individuals with special needs. Ask the same of all specialist providers and therapist providers**
- start looking for day program and vocational programs during high school and even before bridge/transition program if those services are not embedded into your school system**
- work with case manager through CMA to complete all the steps needed to transition to and qualify for adult medicaid waivers**
- ask primary caregiver for guardianship letter and provide them with relevant information they should add as outlined by case manager or legal team**

Best practices for working with primary care doctor

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- yearly physicals (even if specialists handle most of care primary signs bulk of the paperwork)
- be organized to best of your ability with medication lists, question lists, recent list of specialist visits and updates if possible
- make sure means of efficient communication(use portal as much as possible providers are too busy to call back!)
- give heads up with a portal message for new issues and concerns so they can be prepared before appointment
- alert them of hospitalizations so they can review records from the hospital before follow up appointments
- get to know MA that works closest with your provider
- get to know referral coordinator if there is one in the office
- when letter of medical necessity is requested try to work with case manager with Case Management Agency, Home Health Company attendant or therapist to draft a template so provider knows what information is needed. Same for peer to peers requested for Private Duty Nursing or Certified Nursing Assistant Services

Best practices for working with specialists

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- request to go on cancellation waitlist or be willing to go to different campus if it reduces wait time
- be compliant with appointments do not no show if you can avoid it since wait times to get in are so long
- make sure means of efficient communication(use portal as much as possible providers are too busy to call back!)
- give heads up with a portal message for new issues and concerns so they can be prepared before appointment
- alert them of hospitalizations so they can review records from the hospital before follow up appointments i
- get to know nurse or MA that works closest with your provider
- when letter of medical necessity is requested try to work with case manager with Case Management Agency, Home Health Company attendant or therapist to draft a template so provider knows what information is needed. Same for peer to peers requested for Private Duty Nursing or Certified Nursing Assistant Services
- take advantage of complex scheduler through Children's
- if feeling unheard by specialist ask your primary care doctor to make contact and help you advocate for your child
- if your child is medically complex and you have several specialists involved encourage them to communicate with one another request a care conference if there are diagnostic or treatment dilemmas that necessitate this