

## Cerebral Palsy CDE Revision History

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# Cerebral Palsy CDE Revision History

## August 2022

- **Outcomes and Endpoints; Pain Domain/Subdomain**
  - The following New Notices of Copyright were posted on the Cerebral Palsy data standards page:
    - Bath Adolescent Pain Questionnaire (BAPQ); Classification: Supplemental
    - Body Diagram; Classification: Exploratory
    - Brief Pain Inventory (BPI) Long Form; Classification: Supplemental
    - Child Self-Efficacy Scale (CSES); Classification: Exploratory
    - Face, Legs, Activity, Cry, Consolability Scale (FLACC); Classification: Supplemental
    - Noncommunicating Children's Pain Checklist-Revised (NCCPC-R); Classification: Supplemental
    - Pain Interference Index (PII); Classification: Supplemental
    - Pediatric Pain Profile (PPP); Classification: Supplemental
    - Numeric Pain Rating Scale (NPRS); Classification: Supplemental
    - Pediatric Pain Questionnaire (PPQ); Classification: Exploratory
    - Visual Analog Scale (VAS); Classification: Supplemental
  - The following NOCs shared with other disorders were added on the CP data standards page:
    - Brief Pain Inventory (BPI) Short Form; Classification: Supplemental
    - Child Activity Limitations Interview (CALI); Classification: Exploratory
    - Faces Pain Scale-Revised (FPS-R); Classification: Supplemental
    - PROMIS Pain Behavior Short Forms; Classification: Exploratory
    - PROMIS Pain Interference Short Forms; Classification: Supplemental
- **Outcomes and Endpoints; Functional Outcomes Domain/Subdomain**
  - The following New Notice of Copyright was posted on the Cerebral Palsy data standards page
    - Edinburgh Visual Gait Score (EVGS); Classification: Supplemental
- **Treatment/Intervention Data; Surgeries and Other Procedures Domain; Subdomain**
  - The following New CRF and CDEs were posted on the CP data standards page:
    - Lower Extremity Orthopedic Surgical Procedures – Ankle

### Lower Extremity Orthopedic Surgical Procedures – Ankle CRF Supplemental CDEs

CDE ID	CDE Name
C59242	Surgical procedure orthopedic ankle type
C59312	Surgery procedure gastrocnemius resection ankle perform indicator
C59313	Surgery procedure gastrocnemius resection ankle laterality type
C59314	Surgery procedure gastrocnemius resection left ankle type
C59315	Surgery procedure gastrocnemius resection right ankle type
C59316	Surgery procedure achilles tendon lengthen ankle perform indicator
C59317	Surgery procedure achilles tendon lengthen ankle laterality type
C59318	Surgery procedure achilles tendon lengthen left ankle type
C59319	Surgery procedure achilles tendon lengthen right ankle type
C59320	Surgery procedure anterior tibialis tendon transfer ankle perform indicator

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C59321	Surgery procedure anterior tibialis tendon transfer ankle laterality type
C59322	Surgery procedure anterior tibialis tendon transfer left ankle type
C59323	Surgery procedure anterior tibialis tendon transfer left ankle split anatomic site
C59324	Surgery procedure anterior tibialis tendon transfer left ankle complete anatomic site
C59325	Surgery procedure anterior tibialis tendon transfer right ankle type
C59326	Surgery procedure anterior tibialis tendon transfer right ankle split anatomic site
C59327	Surgery procedure anterior tibialis tendon transfer right ankle complete anatomic site
C59328	Surgery procedure posterior tibialis tendon transfer ankle perform indicator
C59329	Surgery procedure posterior tibialis tendon transfer ankle laterality type
C59330	Surgery procedure posterior tibialis tendon transfer left ankle type
C59331	Surgery procedure posterior tibialis tendon transfer left ankle split anatomic site
C59332	Surgery procedure posterior tibialis tendon transfer left ankle complete anatomic site
C59333	Surgery procedure posterior tibialis tendon transfer right ankle type
C59334	Surgery procedure posterior tibialis tendon transfer right ankle split anatomic site
C59335	Surgery procedure posterior tibialis tendon transfer right ankle complete anatomic site
C59336	Surgery procedure posterior tibialis lengthen ankle perform indicator
C59337	Surgery procedure posterior tibialis lengthen ankle laterality type
C59338	Surgery procedure posterior tibialis lengthen left ankle type
C59339	Surgery procedure posterior tibialis lengthen right ankle type
C59340	Surgery procedure toe flexor lengthen ankle perform indicator
C59341	Surgery procedure toe flexor lengthen ankle perform type
C59342	Surgery procedure toe flexor lengthen ankle laterality type
C59343	Surgery procedure toe flexor lengthen left ankle anatomic site
C59344	Surgery procedure toe flexor lengthen right ankle anatomic site
C59345	Surgery procedure toe flexor lengthen tenotomy laterality type
C59346	Surgery procedure toe flexor lengthen tenotomy left ankle anatomic site
C59347	Surgery procedure toe flexor lengthen tenotomy right ankle anatomic site
C59348	Surgery procedure plantar fascia release ankle perform indicator
C59349	Surgery procedure plantar fascia release ankle laterality type
C59350	Surgery procedure plantar fascia release left ankle type
C59351	Surgery procedure plantar fascia release right ankle type
C59352	Surgery procedure tibial derotational osteotomy ankle perform indicator
C59353	Surgery procedure tibial derotational osteotomy ankle perform type
C59354	Surgery procedure tibial derotational osteotomy external ankle laterality type
C59355	Surgery procedure tibial derotational osteotomy external left ankle anatomic site
C59356	Surgery procedure tibial derotational osteotomy external right ankle anatomic site
C59357	Surgery procedure tibial derotational osteotomy internal ankle laterality type
C59358	Surgery procedure tibial derotational osteotomy internal left ankle anatomic site
C59359	Surgery procedure tibial derotational osteotomy internal right ankle anatomic site
C59360	Surgery procedure hindfoot arthrodesis ankle perform indicator
C59361	Surgery procedure hindfoot arthrodesis ankle laterality type

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C59362	Surgery procedure hindfoot arthrodesis left ankle anatomic site
C59363	Surgery procedure hindfoot arthrodesis right ankle anatomic site
C59364	Surgery procedure calcaneal osteotomy ankle perform indicator
C59365	Surgery procedure calcaneal osteotomy ankle laterality type
C59366	Surgery procedure calcaneal osteotomy left ankle type
C59367	Surgery procedure calcaneal osteotomy left ankle sliding anatomic site
C59392	Surgery procedure calcaneal osteotomy right ankle type
C59396	Surgery procedure calcaneal osteotomy right ankle sliding anatomic site
C59397	Surgery procedure midfoot osteotomy ankle perform indicator
C59398	Surgery procedure midfoot osteotomy ankle laterality type
C59399	Surgery procedure midfoot osteotomy left ankle anatomic site
C59400	Surgery procedure midfoot osteotomy right ankle anatomic site
C59401	Surgery procedure first metatarsal osteotomy arthrodesis ankle perform indicator
C59402	Surgery procedure first metatarsal osteotomy arthrodesis ankle laterality type
C59403	Surgery procedure first metatarsal osteotomy arthrodesis left ankle type
C59404	Surgery procedure first metatarsal osteotomy arthrodesis right ankle type

- **Treatment/Intervention Data; Surgeries and Other Procedures Domain; Subdomain**
  - The following New CRF and CDEs were posted on the CP data standards page:
    - Lower Extremity Orthopedic Surgical Procedures – Knee

### Lower Extremity Orthopedic Surgical Procedures – Knee Supplemental CDEs

CDE ID	CDE Name
C59207	Surgical procedure orthopedic knee type
C59208	Surgery procedure anterior hemi epiphyseodesis knee perform indicator
C59209	Surgery procedure anterior hemi epiphyseodesis knee laterality type
C59210	Surgery procedure anterior hemi epiphyseodesis left knee type
C59211	Surgery procedure anterior hemi epiphyseodesis left knee other text
C59212	Surgery procedure anterior hemi epiphyseodesis right knee type
C59213	Surgery procedure anterior hemi epiphyseodesis right knee other text
C59214	Surgery procedure distal femoral extension osteotomy knee perform indicator
C59215	Surgery procedure distal femoral extension osteotomy knee laterality type
C59216	Surgery procedure distal femoral extension osteotomy left knee type
C59217	Surgery procedure distal femoral extension osteotomy left knee other text
C59218	Surgery procedure distal femoral extension osteotomy right knee type
C59219	Surgery procedure distal femoral extension osteotomy right knee other text
C59220	Surgery procedure hamstring lengthen knee perform indicator
C59221	Surgery procedure hamstring lengthen knee perform type
C59222	Surgery procedure hamstring lengthen percutaneous knee laterality type
C59223	Surgery procedure hamstring lengthen percutaneous left knee anatomic site
C59224	Surgery procedure hamstring lengthen percutaneous right knee anatomic site
C59225	Surgery procedure hamstring lengthen percutaneous left knee anatomic site other text

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C59226	Surgery procedure hamstring lengthen percutaneous right knee anatomic site other text
C59227	Surgery procedure hamstring lengthen open knee laterality type
C59228	Surgery procedure hamstring lengthen open left knee anatomic site
C59229	Surgery procedure hamstring lengthen open right knee anatomic site
C59230	Surgery procedure hamstring lengthen open left knee anatomic site other text
C59231	Surgery procedure hamstring lengthen open right knee anatomic site other text
C59232	Surgery procedure semitendinosus transfer adductor magnus knee perform indicator
C59233	Surgery procedure semitendinosus transfer adductor magnus knee perform laterality type
C59234	Surgery procedure patellar tendon shorten advance perform indicator
C59235	Surgery procedure patellar tendon shorten advance knee perform laterality type
C59236	Surgery procedure patellar tendon shorten advance left knee type
C59237	Surgery procedure patellar tendon shorten advance right knee type
C59238	Surgery procedure rectus femoris release transfer knee perform indicator
C59239	Surgery procedure rectus femoris release transfer knee laterality type
C59240	Surgery procedure rectus femoris release transfer left knee type
C59241	Surgery procedure rectus femoris release transfer left knee anatomic site
C59243	Surgery procedure rectus femoris release transfer right knee type
C59244	Surgery procedure rectus femoris release transfer right knee anatomic site

- **Treatment/Intervention Data; Surgeries and Other Procedures Domain; Subdomain**
  - The following New CRF and CDEs were posted on the CP data standards page:
    - Lower Extremity Orthopedic Surgical Procedures – Hip

### Lower Extremity Orthopedic Surgical Procedures – Hip CRF Supplemental CDEs

CDE ID	CDE Name
C59039	Surgical procedure orthopedic hip type
C59249	Surgery procedure adductor lengthen hip perform indicator
C59250	Surgery procedure adductor lengthen hip perform type
C59251	Surgery procedure adductor lengthen percutaneous hip laterality type
C59252	Surgery procedure adductor lengthen percutaneous left hip anatomic site
C59253	Surgery procedure adductor lengthen percutaneous right hip anatomic site
C59254	Surgery procedure adductor lengthen percutaneous left hip anatomic site other text
C59255	Surgery procedure adductor lengthen percutaneous right hip anatomic site other text
C59256	Surgery procedure adductor lengthen open hip laterality type
C59257	Surgery procedure adductor lengthen open left hip anatomic site
C59258	Surgery procedure adductor lengthen open right hip anatomic site
C59259	Surgery procedure adductor lengthen open left hip anatomic site other text
C59260	Surgery procedure adductor lengthen open right hip anatomic site other text
C59261	Surgery procedure adductor lengthen neurectomy hip laterality type
C59262	Surgery procedure psoas lengthen hip perform indicator
C59263	Surgery procedure psoas lengthen hip perform type
C59264	Surgery procedure psoas lengthen percutaneous hip laterality type

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C59265	Surgery procedure psoas lengthen percutaneous left hip anatomic site
C59266	Surgery procedure psoas lengthen percutaneous right hip anatomic site
C59267	Surgery procedure psoas lengthen percutaneous left hip anatomic site other text
C59268	Surgery procedure psoas lengthen percutaneous right hip anatomic site other text
C59269	Surgery procedure psoas lengthen open hip laterality type
C59270	Surgery procedure open psoas lengthen left hip anatomic site
C59271	Surgery procedure psoas lengthen open right hip anatomic site
C59272	Surgery procedure psoas lengthen open left hip anatomic site other text
C59273	Surgery procedure psoas lengthen open right hip anatomic site other text
C59274	Surgery procedure hip femoral derotation osteotomy perform indicator
C59275	Surgery procedure femoral derotation osteotomy hip laterality type
C59276	Surgery procedure femoral derotation osteotomy left hip anatomic site
C59277	Surgery procedure femoral derotation osteotomy right hip anatomic site
C59278	Surgery procedure femoral derotation osteotomy left hip anatomic site other text
C59279	Surgery procedure femoral derotation osteotomy right hip anatomic site other text
C59280	Surgery procedure varus derotational osteotomy proximal femur hip perform indicator
C59281	Surgery procedure varus derotational osteotomy proximal femur hip laterality type
C59282	Surgery procedure varus derotational osteotomy proximal femur left hip neck shaft angle value
C59283	Surgery procedure varus derotational osteotomy proximal femur right hip neck shaft angle value
C59284	Surgery procedure varus derotational osteotomy proximal femur left hip type
C59285	Surgery procedure varus derotational osteotomy proximal femur right hip type
C59286	Surgery procedure varus derotational osteotomy proximal femur left hip type other text
C59287	Surgery procedure varus derotational osteotomy proximal femur right hip type other text
C59288	Surgery procedure hip pelvic osteotomy perform indicator
C59289	Surgery procedure pelvic osteotomy hip laterality type
C59290	Surgery procedure pelvic osteotomy left hip perform type
C59291	Surgery procedure pelvic osteotomy right hip perform type
C59292	Surgery procedure pelvic osteotomy left hip perform type other text
C59293	Surgery procedure pelvic osteotomy right hip perform type other text
C59294	Surgery procedure hip open reduction perform indicator
C59295	Surgery procedure open reduction hip laterality type
C59296	Surgery procedure open reduction left hip perform type
C59297	Surgery procedure open reduction right hip perform type
C59298	Surgery procedure open reduction left hip perform type other text
C59299	Surgery procedure open reduction right hip perform type other text
C59300	Surgery procedure proximal femoral resection hip perform indicator
C59301	Surgery procedure proximal femoral resection hip laterality type
C59302	Surgery procedure proximal femoral resection left hip anatomic site
C59303	Surgery procedure proximal femoral resection right hip anatomic site
C59304	Surgery procedure proximal femoral resection left hip anatomic site other text
C59305	Surgery procedure proximal femoral resection right hip anatomic site other text

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C59306	Surgery procedure arthroplasty hip perform indicator
C59307	Surgery procedure arthroplasty hip laterality type
C59308	Surgery procedure arthroplasty left hip perform type
C59309	Surgery procedure arthroplasty right hip perform type
C59310	Surgery procedure arthroplasty left hip perform type other text
C59311	Surgery procedure arthroplasty right hip perform type other text

- **Assessments and Examinations; Imaging Diagnostics Domain; Subdomain**
  - The following New CRF and CDEs were posted on the CP data standards page:

### Pelvic Radiographs CRF Supplemental-Highly Recommended CDEs

CDE ID	CDE Name
C59184	Migration percentage left value
C59185	Migration percentage right value

### Pelvic Radiographs CRF Supplemental-Highly Recommended CDEs

CDE ID	CDE Name
C59182	Acetabular index left measurement
C59183	Acetabular index right measurement
C59186	Pelvic obliquity left measurement
C59187	Pelvic obliquity right measurement
C59188	Triradiate cartilage status

- **Assessments and Examinations Physical/Neurological Examination Domain; Subdomain**
  - The following New CRF and CDEs were posted on the CP data standards page:

### Lower Extremity Passive Range of Motion Physical Exam CRF Supplemental CDEs

CDE ID	CDE Name
C59405	Passive range motion hip joint type
C59406	Passive range motion hip joint left side flexion measurement value
C59407	Passive range motion hip joint right side flexion measurement value
C59408	Passive range motion hip joint left side extension measurement value
C59409	Passive range motion hip joint right side extension measurement value
C59413	Passive range motion hip joint left side Thomas Test measurement value
C59415	Passive range motion hip joint right side Thomas Test measurement value
C59417	Passive range motion hip joint left side internal rotation measurement value
C59418	Passive range motion hip joint right side internal rotation measurement value
C59419	Passive range motion hip joint left side external rotation measurement value
C59421	Passive range motion hip joint right side external rotation measurement value
C59422	Passive range motion hip joint left side abduction measurement value
C59423	Passive range motion hip joint right side abduction measurement value
C59424	Passive range motion hip joint left side adduction measurement value
C59425	Passive range motion hip joint right side adduction measurement value

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C59428	Passive range motion knee joint type
C59432	Passive range motion knee joint left side flexion measurement value
C59434	Passive range motion knee joint right side flexion measurement value
C59436	Passive range motion knee joint left side extension measurement value
C59437	Passive range motion knee joint right side extension measurement value
C59441	Passive range motion knee joint left side popliteal angle measurement value
C59442	Passive range motion knee joint right side popliteal angle measurement value
C59443	Passive range motion knee joint left side Ely Test measurement value
C59444	Passive range motion knee joint right side Ely Test measurement value
C59445	Passive range motion knee joint left side thigh foot angle measurement value
C59446	Passive range motion knee joint right side thigh foot angle measurement value
C59447	Passive range motion knee joint left side transmalleolar angle measurement value
C59448	Passive range motion knee joint right side transmalleolar angle measurement value
C59449	Passive range motion ankle joint type
C59450	Passive range motion ankle joint left side knee extend dorsiflexion measurement value
C59451	Passive range motion ankle joint right side knee extend dorsiflexion measurement value
C59452	Passive range motion ankle joint left side knee flex dorsiflexion measurement value
C59453	Passive range motion ankle joint right side knee flex dorsiflexion measurement value
C59454	Passive range motion ankle joint left side plantarflexion measurement value
C59455	Passive range motion ankle joint right side plantarflexion measurement value

- **Assessments and Examinations Vital Signs and Other Body Measures Domain; Subdomain**
  - The following New CRF and CDEs were posted on the CP data standards page:

### Gait Analysis CRF Supplemental – Highly Recommended CDEs

CDE ID	CDE Name
C58879	Assistive device use indicator
C58880	Assistive device type
C59189	Assistive device type other text
C59194	Gait velocity barefoot condition measurement
C59195	Gait cadence barefoot condition measurement
C59196	Gait stride length barefoot condition left measurement
C59197	Gait stride length barefoot condition right measurement
C59245	Gait step length barefoot condition left measurement
C59246	Gait step length barefoot condition right measurement
C59203	Gait velocity orthotic condition measurement
C59204	Gait cadence orthotic condition measurement
C59205	Gait stride length orthotic condition left measurement
C59206	Gait stride length orthotic condition right measurement
C59247	Gait step length orthotic condition left measurement
C59248	Gait step length orthotic condition right measurement

### Gait Analysis CRF Supplemental CDEs



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CDE ID	CDE Name
C59190	Gait deviation index barefoot condition score
C59191	Gait profile score barefoot condition overall value
C59192	Gait profile score barefoot condition left value
C59193	Gait profile score barefoot condition right value
C59198	Gait orthosis type text
C59199	Gait deviation index orthotic condition score
C59200	Gait profile score orthotic condition overall value
C59201	Gait profile score orthotic condition left value
C59202	Gait profile score orthotic condition right value

### February 2020

- The Participant Condition Characteristics case report form was posted on the Cerebral Palsy data standards page.
- New Supplemental – Highly Recommended CDEs added to the case report form include:
  - C58653 Cerebral palsy predominant motor type
  - C58654 Cerebral palsy secondary motor type
  - C58662 Predominant MRI brain pattern type
  - C58663 Cerebral palsy gross motor function type
  - C58664 Cerebral palsy fine motor function type
  - C58665 Cerebral palsy upper limb function type
  - C58666 Communication type
  - C58667 Eating drinking type
- New Supplemental CDEs added to the case report form include:
  - C58655 Cerebral palsy distribution type
  - C58656 Cerebral palsy distribution primarily unilateral type
  - C58657 Hemiplegia laterality type
  - C58658 Monoplegia laterality type
  - C58659 Cerebral palsy distribution primarily bilateral type
  - C58660 Timing injury abnormality type
  - C58661 Post-neonatal specific exact cause text
  - C05460 Seizure indicator
  - C58668 Intellectual impairment type
  - C58669 Visual impairment indicator
  - C58670 Visual impairment severity type
  - C58671 Hearing impairment indicator
  - C58672 Hearing impairment severity type
  - C58673 Respiratory ventilation support assist indicator
  - C58674 Respiratory ventilation support assist type
  - C58675 Respiratory ventilation support assist other type text

# Cerebral Palsy CDE Revision History

## January 2020

- General Core CRF updated to replace 'Gender' question with 'Sex assigned at birth' and 'Gender identity'.
- Two new CDEs added to CRF: C58676 (Sex assigned at birth) and C58677 (Gender identity). C00035 has been removed
- Start-Up document updated to reflect these changes.

## August 2019

- The Modified Ashworth Scale – Limb Tone Testing was moved from the Domain; Subdomain Assessments and Examinations; Physical and Neurological Examination to the Domain; Subdomain Outcomes and End Points; Spasticity / Movement.

## December 2018

- The External Device – CP case report form was posted on the Cerebral Palsy data standards page.
- New CDEs added to the case report form include: C56951, C56952, C56953, C56954, C58470, C58471, C58472, C58473, C58474, C58475, C58476, C58477, C58478, C58479, C58480, C58481, C58482, C58483, C58484, C58485, C58486, C58487, C58488, C58489, C58490, C58491, C58492, C58493, C58494, C58495, C58496, C58497, C58498, C58499, C58500, C58501, C58502, C58503, C58504, C58505, C58506, C58507, C58508, C58509, C58510, C58511, C58512, C58513, C58563, C58564, C58565, C58566, C58567, C58568, C58569, C58570, C58571, C58572, C58573, C58574, C58575, C58576, C58577, C58578, C58617, C58618, C58619, C58620, C58621, C58622, C58623, C58624, C58625, and C58626.
- The term 'subject' was removed from the question text for CDEs C12679, C12682, C12673, C58471, C58470, and C58472.
- The permissible value term 'Stroller' was revised to 'Medical/Adaptive Stroller' for CDE C12683.
- The permissible value term 'Inserts of any type' was revised to 'Shoe Inserts of any type' for CDE 58478.
- 'Thumb' was added as a permissible value for CDEs C58481 and C58483.
- Disease specific instructions were added to CDEs C18870, C58566, C58489, C58621, C58622, C58623, C58619, C58493, C58624, C58625, C58626, C58503, C58508, C58509, and C58617.
- Permissible values were revised for CDE C58488 from Position Device;Stander;Body jacket/Thoracic-lumbar-sacral orthoses (TLSO);Other, specify to 'Seated or Lying Position Device;Stander;Truncal Support Devices;Other, specify'
- The permissible value term 'Lift System' was revised to 'Lift system (e.g., Hoyer, ceiling track system)' for CDE C58499.

## July 2017

- The Participant Characteristics and Disease Injury Related Events Working Group Summary was updated.

## Cerebral Palsy CDE Revision History

### March 2017

- The Surgical and Hospitalization History CRF was updated to include:  
'type of Neurological surgery:  
 Selective dorsal rhizotomy (SDR)  Baclofen pump placement;' and  
'type of Bone orthopedic surgery?  
 Ankle/foot surgery  Elbow surgery  Hip surgery  Knee surgery  Shoulder surgery  
 Wrist surgery'
- The Behavioral History CRF was reformatted to be 508 compliant.
- The Medical History form was updated to include Optic atrophy and Visual field deficits under Eyes section and Epilepsy type to include the PVs 'Medically intractable' and 'Well controlled' under the Neurological History section.
- The Neuromotor Skill Functional Assessments Working Group Summary was updated.

### January 2017

- The email address to obtain permission to use the Segmental Assessment of Trunk Control ( SATCo) was revised.
- Errors in the Neuroimaging Cerebral Palsy Magnetic Resonance Imaging CRF were corrected.
- The Neuroimaging Diagnostics Working Group Summary was posted to the NINDS CDE website.

### December 2016

- Cerebral Palsy CDEs were posted to the NINDS CDE Website.