



ASH1L.ORG

FAMILY-FOUNDED INFORMATION & RESEARCH

COMPREHENSIVE OPTIONAL MODULES

Comprehensive Parent & Caregiver Questionnaire

A save-and-return record of strengths, priorities, development, health, communication, and daily life. Complete only the sections that help.

FILLABLE PDF

SAVE AND RETURN | US LETTER

FIFTEEN CLINICAL AREAS

BUILT WITH AND FOR THE ASH1L COMMUNITY

Thank you to every family and individual who has shared time, questions, observations, or ideas. Every contribution helps the next family and the next research question.



Quick start: save, complete, and share

This PDF stays on your device unless you choose to share it. Complete only the sections that are useful.

PRIVATE INFORMATION

A completed copy may contain health, school, genetic, and contact information. Store it where you choose. Share only the pages and people you choose. Do not email records or this completed form to an unknown or public address.

1 DOWNLOAD AND SAVE A COPY

Open the saved file in a PDF app that supports forms. Save again after each module. Test by closing and reopening before entering a long history.

2 START WITH STRENGTHS AND PRIORITIES

Complete page 3 first. It gives a one-page summary even if you stop there.

3 CHOOSE ONLY RELEVANT MODULES

Use the module map on page 4. Estimated times are guides, not expectations. Skip anything that is not useful or feels too sensitive.

4 KEEP SOURCES SEPARATE

Person or family observation, original records, clinician reports, and school or therapy reports are different source types. Select the one that supports each entry.

CLINICAL SAFETY

This tool does not replace medical care, diagnosis, treatment advice, or emergency monitoring. For urgent symptoms, contact the person's clinician or local emergency services.



One-page priority summary

Complete this page first. It is designed to stand alone for an appointment, school meeting, or family planning conversation.

NAME OR FAMILY-CHOSEN CASE LABEL

CURRENT AGE

DATE UPDATED

STRENGTHS, INTERESTS AND WHAT BRINGS JOY

TOP THREE PRIORITIES RIGHT NOW

family-defined

USUAL BASELINE: COMMUNICATION, MOVEMENT, SLEEP, COMFORT AND PARTICIPATION

CURRENT CHANGE OR QUESTION

SAFETY INFORMATION OR SUPPORTS THAT SHOULD BE KNOWN FIRST



Choose your path

Check only the modules you need. The fifteen clinical areas organize the questionnaire; blank sections remain unanswered, not negative.

☐

PROFILE & PREFERENCES

pages 5-9

10-20 min

☐

GENETICS

pages 10-13

15-25 min

☐

HISTORY & SUPPORTS

pages 14-25

35-60 min

☐

15 CLINICAL AREAS

pages 26-56

select relevant areas

☐

RESPONSES & CHANGE

pages 57-61

15-30 min

☐

COMMUNICATION & LIFESPAN

pages 62-70

select relevant ages

☐

ADULT, FUNCTION & SAFETY

pages 71-75

15-30 min

☐

REVIEW & SHARE

pages 76-80

15-25 min

MY PLAN FOR COMPLETING OR SHARING THIS DOCUMENT



SECTION 01

Profile & preferences

Identify the person on your terms, record communication access, and note the best way to make contact before adding clinical detail.

MODULES IN THIS SECTION

Identity, language & access

5-10 min

Contact preferences

3-5 min

Sharing plan

5-8 min



Person and household profile

Use a name or case label. Share only what is useful for your purpose.

SHARE LESS WHEN LESS IS ENOUGH

A case label and age range may be enough for many conversations. Exact dates and locations can increase identifiability.

NAME OR FAMILY-CHOSEN CASE LABEL

DATE OF BIRTH (OPTIONAL)

CURRENT AGE OR AGE RANGE

SEX / GENDER, IF THE PERSON CHOOSES TO SHARE

COUNTRY / REGION (NO STREET ADDRESS NEEDED)

PERSON COMPLETING THIS FORM AND RELATIONSHIP

HOUSEHOLD OR CARE TEAM MEMBERS IMPORTANT TO THIS HISTORY



Language, communication & access

Record how the person communicates and what makes a conversation, appointment, or form more accessible.

PREFERRED SPOKEN, SIGNED OR WRITTEN LANGUAGE(S)

HOW THE PERSON COMMUNICATES YES / NO / STOP / PAIN / CHOICE

COMMUNICATION MODES (SPEECH, GESTURE, SIGN, PICTURES, AAC, WRITING, OTHER)

INTERPRETER, TRANSLATION OR ACCESS NEEDS

PROCESSING TIME, SENSORY OR ENVIRONMENTAL SUPPORTS

HOW TO INCLUDE THE PERSON DIRECTLY IN DECISIONS



Contact preference

Record the contact approach that feels most comfortable right now.

WHO MAY CONTACT YOU?

- | | |
|---|---|
| ☐ Direct contact is welcome | ☐ Clinician-mediated contact only |
| ☐ Private one-to-one contact first | ☐ Email or written contact only |
| ☐ No contact at this time | ☐ Not sure - ask before proceeding |

PREFERRED CONTACT NAME OR LABEL

EMAIL / PHONE / OTHER METHOD (OPTIONAL)

BEST DAYS, TIMES, TIME ZONE OR RESPONSE WINDOW

LANGUAGE OR INTERPRETER NEED

PEOPLE WHO SHOULD OR SHOULD NOT BE INCLUDED

SAVES LOCALLY

This PDF does not send itself or add you to a list. Contact details remain in the copy you save.



Plan who may receive this copy

Choose separately for each possible reader. You can change these choices for a future copy.

01 Keep as private family notes ☐ Yes ☐ No ☐ Not sure

02 Share selected pages with a clinician ☐ Yes ☐ No ☐ Not sure

03 Share selected pages with a school or therapy team ☐ Yes ☐ No ☐ Not sure

04 Share selected pages for a specialist referral ☐ Yes ☐ No ☐ Not sure

05 Use selected details in an initial research conversation ☐ Yes ☐ No ☐ Not sure

06 Use selected details in a community conversation ☐ Yes ☐ No ☐ Not sure

07 Share a records list with a trusted professional ☐ Yes ☐ No ☐ Not sure

08 Include photographs, video, audio, or other media ☐ Yes ☐ No ☐ Not sure

SEND ONLY WHAT HELPS

A completed questionnaire stays in the file you save. Select the useful pages, check identifiers, and send them only to a known recipient.



SECTION 02

Genetics

Copy what a report says without turning a laboratory result into a prediction. Classification, inheritance, parental testing, and additional findings each answer different questions.

MODULES IN THIS SECTION

Report at a glance

5-8 min

Classification & VUS boundaries

5-8 min

Inheritance, parental testing & additional findings

5-10 min



Genetic report at a glance

Copy exact report wording when available. A blank means not known or not entered.

KEEP THE ORIGINAL WORDING

Transcript, genome build, zygoty and CNV coordinates can change how a finding is interpreted. Do not guess missing pieces.

LABORATORY / REPORT NAME

REPORT DATE

GENE AND TRANSCRIPT AS WRITTEN

DNA-LEVEL VARIANT WORDING (c. OR GENOMIC, IF REPORTED)

PROTEIN-LEVEL WORDING (p., IF REPORTED)

VARIANT TYPE OR CNV DESCRIPTION AS WRITTEN

REPORT IMPRESSION / INTERPRETATION - COPY, DO NOT PARAPHRASE



Classification & VUS boundaries

Record the laboratory classification and date. Classification can change; it is not the same as a person's clinical course.

LABORATORY CLASSIFICATION

- | | |
|--|--|
| ☐ Pathogenic | ☐ Likely pathogenic |
| ☐ Variant of uncertain significance (VUS) | ☐ Likely benign |
| ☐ Benign | ☐ Other / unclear |

CLASSIFICATION DATE AND LABORATORY

EVIDENCE OR COMMENTS LISTED BY THE LAB

HAS THE RESULT BEEN REINTERPRETED OR AMENDED?

WHAT A VUS DOES NOT MEAN

A VUS is not proof that the variant explains a person's history. Do not use this questionnaire to reclassify a VUS. Keep laboratory classification, clinician interpretation, and family observation in separate fields.

QUESTIONS FOR GENETICS OR THE ORDERING CLINICIAN



Inheritance, parental testing & additional findings

Record what testing established. Family assumptions and formal results should not be merged.

INHERITANCE AS REPORTED

☐ De novo ☐ Inherited ☐ Not tested ☐ Unknown ☐ Other

PARENTAL / FAMILY TESTING COMPLETED AND RESULT WORDING

SEGREGATION OR MOSAICISM COMMENTS FROM THE REPORT / CLINICIAN

OTHER GENETIC OR COPY-NUMBER FINDINGS

WHICH FINDING(S) DOES THE CLINICIAN CONSIDER RELEVANT, AND WHY?

GENETICS FOLLOW-UP OR REANALYSIS PLAN



SECTION 03

History & current supports

Build the shared history once: pregnancy and birth, milestones, current diagnoses and medications, services, education, family history, and source records.

MODULES IN THIS SECTION

Pregnancy, birth & development

20-30 min

Current care & supports

15-25 min

Education, family history & records

15-25 min



Prenatal history

Sensitive details are optional. Choose 'Prefer not to answer' whenever needed.

NO CAUSATION IS ASSUMED

A time-linked pregnancy event is recorded as chronology. This page does not determine whether an event caused a later finding.

PREGNANCY COURSE AND PRENATAL CARE

ILLNESS, MEDICATION OR EXPOSURE THE FAMILY CHOOSES TO RECORD

PRENATAL IMAGING, TESTING OR GROWTH COMMENTS

MOVEMENT, POSITION, FLUID OR PLACENTAL CONCERNS

SOURCE: FAMILY MEMORY, PRENATAL RECORD OR CLINICIAN SUMMARY



Birth, newborn & NICU

Record what is known from family memory and original records as separate sources.

GESTATIONAL AGE AND DELIVERY TYPE

BIRTH WEIGHT, LENGTH AND HEAD SIZE, IF KNOWN

APGAR OR DELIVERY-ROOM SUPPORT, IF RECORDED

NICU, OXYGEN, JAUNDICE, LOW BLOOD SUGAR, TEMPERATURE OR INFECTION

EARLY FEEDING, BREATHING, TONE, ALERTNESS OR SLEEP

DISCHARGE SUMMARY OR SOURCE LIMITS



Developmental milestones: early movement & communication

Approximate ages are useful. 'Not yet', 'not sure' and 'different sequence' are valid entries.

MILESTONE	AGE / RANGE / NOT YET	SOURCE OR NOTE
Social smile / shared enjoyment		
Head control		
Rolling		
Sitting independently		
Crawling or other floor mobility		
Independent walking		
Babbling / varied vocal play		
First words or consistent approximations		
Combining words / symbols		
Pointing, showing or shared attention		

DIFFERENT SEQUENCE, ADAPTATION OR CONTEXT THAT MATTERS



Developmental access, plateaus & change

Describe access to skills over time. Avoid forcing a complex pattern into a single 'regression' label.

WORDS MATTER

Use the family's description and source wording. 'Could not access', 'stopped using', 'lost', and 'not observed' are not automatically equivalent.

SKILLS THAT ARE CONSISTENT AND RELIABLE

SKILLS THAT REQUIRE PROMPTING, SUPPORT OR THE RIGHT STATE

PLATEAUS OR PERIODS OF SLOWER PROGRESS

SKILLS DESCRIBED AS LOST, TEMPORARILY UNAVAILABLE OR LATER REGAINED

AGE / DATE, CONTEXT, RECOVERY AND SOURCE FOR IMPORTANT CHANGES



Current diagnoses & clinical labels

List who made each diagnosis and when, if known. A suspected concern and a formal diagnosis are different.

CURRENT FORMAL DIAGNOSES

SUSPECTED OR UNDER-EVALUATION CONCERNS

DIAGNOSES LATER REVISED, REMOVED OR QUESTIONED

CURRENT CLINICAL PRIORITIES

SOURCE LIMITS OR DATE THIS SNAPSHOT WAS UPDATED



Current medications, supplements & allergies

Record the current list and its source. This page is not a dosing recommendation.

NAME	DOSE / ROUTE / SCHEDULE	REASON / PRESCRIBER	START / NOTE

ALLERGIES, INTOLERANCES OR ADVERSE REACTIONS

HOW THIS LIST WAS VERIFIED AND DATE UPDATED



Surgeries, procedures, equipment & current supports

Record chronology and recovery without assuming that a time-linked change was caused by the procedure.

SURGERIES OR PROCEDURES: DATE, TYPE AND REASON

ANESTHESIA OR SEDATION USED, IF KNOWN

RECOVERY, CONSTIPATION, SLEEP, PAIN, REGULATION OR SKILL-ACCESS CHANGE

EQUIPMENT: AAC, MOBILITY, ORTHOTICS, FEEDING, HEARING, VISION OR OTHER

SAFETY PLANS, RESCUE MEDICATIONS OR EMERGENCY INFORMATION



Providers, services & goals

List only the providers or services relevant to this working document.

PROVIDER / SERVICE	SETTING / FREQUENCY	CURRENT GOAL OR QUESTION	LAST SEEN

CARE-TEAM COORDINATION OR ACCESS BARRIERS



Education, early intervention, work & participation

Use the terms that fit the person's country and age. IEP and 504 are examples, not universal labels.

CURRENT PROGRAM, SCHOOL, TRAINING, COLLEGE, WORK OR DAY SETTING

SCHEDULE, CLASS / ROLE TYPE AND ATTENDANCE PATTERN

SUPPORT PLAN: IEP, 504 OR COUNTRY / PROGRAM EQUIVALENT

THERAPY, AIDE, COMMUNICATION, SENSORY, MOBILITY OR HEALTH SUPPORTS

STRENGTHS, INTERESTS AND CONDITIONS FOR SUCCESS

BARRIERS, ABSENCES, FATIGUE OR CHANGING ACCESS



Family history

Share only what is relevant and permitted. A family history item does not establish cause or inheritance.

- | | |
|---|--|
| ☐ Speech/language difference | ☐ Autism |
| ☐ ADHD | ☐ Learning difference |
| ☐ Intellectual disability | ☐ Seizure/epilepsy |
| ☐ Movement disorder/tics | ☐ Genetic condition |
| ☐ Immune/autoimmune concern | ☐ Allergy/asthma/eczema |
| ☐ GI/motility concern | ☐ Cardiac rhythm concern |
| ☐ Bone/connective concern | ☐ Endocrine/puberty/thyroid |
| ☐ Mental-health concern | ☐ Other relevant history |

WHO IS AFFECTED AND WHAT IS FORMALLY DIAGNOSED VS REPORTED

CONSANGUINITY, REPRODUCTIVE HISTORY OR SENSITIVE DETAIL - OPTIONAL

SOURCE AND SHARING LIMITS



Source & records inventory

Record what exists. Do not attach records to a public website. Use a separately agreed secure process if review is requested.

AVAILABLE OR KNOWN TO EXIST

- | | |
|--|--|
| ☐ Genetic report | ☐ Developmental evaluation |
| ☐ Neurology note | ☐ EEG report/data access |
| ☐ MRI / PET / CT report | ☐ Sleep study |
| ☐ ENT / audiology | ☐ Ophthalmology / vision |
| ☐ GI / motility | ☐ Immunology / allergy |
| ☐ Endocrine / growth | ☐ Cardiology |
| ☐ Urology / renal | ☐ Dermatology / skin |
| ☐ Orthopedics / bone | ☐ PT / OT |
| ☐ SLP / AAC / feeding | ☐ IEP / school testing |
| ☐ Medication / anesthesia | ☐ Emergency / hospitalization |

WHERE RECORDS ARE HELD AND WHO CONTROLS ACCESS

REDACTION OR SHARING LIMITS

RECORDS STAY WITH THE FAMILY

This inventory is not a request to upload or email records. The family decides whether a record is shared, with whom, for what purpose, and for how long.



SECTION 04

15 clinical areas

The same fifteen areas are used throughout this questionnaire. Complete only the areas that are useful; unanswered fields remain unanswered, not negative.

MODULES IN THIS SECTION

Each selected area

8-18 min

Observation page

response + source

Detail page

assessment + context + impact



Clinical area 1 of 15 | Birth / feeding

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Pregnancy, delivery, prematurity, NICU care, oxygen, jaundice, glucose, temperature, or another newborn concern occurred

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Latch, suck, bottle flow, fatigue, popping off, prolonged feeds, low volumes, or unusual feeding support was observed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Reflux, vomiting, coughing, choking, swallow concern, tube feeding, or supplemental nutrition occurred in early life

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Weight gain, length/height, head growth, or the early growth trajectory raised concern

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Early feeding or newborn function changed with illness, sleep, hospitalization, medication, a procedure, or another active factor

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 1 of 15 | Birth / feeding - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ Birth/NICU record

☐ Growth chart

☐ Feeding evaluation

☐ Swallow or nutrition record

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ newborn course

☐ feeding demands

☐ illness

☐ airway

☐ sleep/fatigue

☐ medication/procedure

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 2 of 15 | Genetics

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 The original report records the laboratory, report date, test method, gene, transcript, cDNA change, and protein consequence

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 The laboratory classification and its evidence are preserved exactly as reported

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Inheritance, parental testing, familial segregation, or an unresolved inheritance question is documented

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 CNV boundaries, splice consequence, mosaicism, complex architecture, or another interpretation detail applies

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Additional findings, reanalysis, updated classification, or a second diagnosis remain visible rather than being assigned to ASH1L automatically

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 2 of 15 | Genetics - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ Original genetic report

☐ Parental/family testing

☐ Microarray/CNV report

☐ Reanalysis or updated classification

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ original report

☐ parental testing

☐ reanalysis

☐ classification update

☐ review of additional findings

☐ record not yet available

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 3 of 15 | Development / language

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Motor, language, learning, intellectual, adaptive, autism, ADHD, or another developmental label is recorded

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Speech, motor speech, processing, memory, comprehension, narrative, or word-finding concerns occur

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Skills continued to emerge, plateaued, became inconsistent, were temporarily unavailable, or were documented as lost

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Gestures, signs, pictures, writing, or a speech-generating device support communication

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Developmental or language access changes with illness, sleep, GI state, medication, stress, sensory demands, or fatigue

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 3 of 15 | Development / language - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|---|---|
| ☐ Developmental evaluation | ☐ Neuropsychology/psychology |
| ☐ Speech-language evaluation | ☐ School/adaptive testing |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|-------------------------------------|--|----------------------------------|
| ☐ illness | ☐ sleep/state | ☐ GI/pain |
| ☐ medication | ☐ school demand | ☐ fatigue |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 4 of 15 | Seizure / EEG / spells

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 A diagnosed seizure, suspected seizure, staring spell, drop, altered-awareness event, or unclear episode has occurred

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 An EEG was normal, abnormal, inconclusive, or did not capture the representative event or needed sleep state

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Event awareness, breathing, color, heart rate, movement, duration, and recovery were described

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Fainting, breath-holding, freezing, sleep event, movement event, cardiac event, or another mimic was considered

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 A rescue plan, medication, diet therapy, device, monitoring plan, or event-capture plan is in place

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 4 of 15 | Seizure / EEG / spells - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|---|---|
| ☐ Routine EEG | ☐ Prolonged/video EEG |
| ☐ Neurology note | ☐ Representative event/rescue plan |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|--|---|-------------------------------------|
| ☐ fever/illness | ☐ waking/sleep | ☐ medication |
| ☐ GI state | ☐ visual/sensory demands | ☐ stress |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 5 of 15 | Sleep / state / fatigue

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01	Sleep onset, night waking, duration, restless sleep, snoring, apnea concern, or unusual sleep movements occur					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
02	Sleep appears prolonged or deep but is not restorative, or sleep stages were not adequately captured					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
03	Waking, morning regulation, daytime fatigue, shutdown, naps, or within-day state affects reliable access					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
04	Language, movement, behavior, pain, or seizure/spell risk appears different after poor or changed sleep					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
05	A sleep study, overnight EEG, actigraphy, home log, or sleep evaluation has been completed					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 5 of 15 | Sleep / state / fatigue - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ Sleep medicine note

☐ Polysomnogram

☐ Overnight EEG

☐ Sleep log/actigraphy

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ ENT/airway

☐ GI/pain

☐ illness

☐ school demands

☐ medication

☐ puberty/hormones

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 6 of 15 | Oral / dental / chewing

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Tooth eruption, retained teeth, enamel, cavities, oral pain, or dental procedures raised concern

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Tongue/lip tie, ulcers, gum bleeding, fragile tissue, saliva, or brushing sensitivity was documented or observed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Biting, tearing, chewing, tongue movement, pocketing, gagging, or swallow timing is difficult or inconsistent

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Choking, drooling, open-mouth posture, atypical jaw movement, or food-safety dependence occurs

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Texture, posture, utensils, self-feeding, pain, sensory demands, or endurance affects oral function

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 6 of 15 | Oral / dental / chewing - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|---|--|
| ☐ Dental record | ☐ Oral-motor evaluation |
| ☐ Feeding therapy note | ☐ Swallow study |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|---------------------------------------|--|----------------------------------|
| ☐ food texture | ☐ fatigue | ☐ illness |
| ☐ oral pain | ☐ sensory demands | ☐ posture |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 7 of 15 | GI / fuel / bowel

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Constipation, retention, withholding, diarrhea, mucus, blood, reflux, vomiting, or abdominal pain occurs

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Bloating, distension, fullness, nausea, burping, satiety, pica, or a motility concern was observed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Intake, hydration, stool pattern, vomiting, weight, glucose/ketone concern, or energy state changes together

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Meals, fasting, hydration, low intake, or GI symptoms appear to change sleep, behavior, communication, movement, pain, or participation

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 A GI, nutrition, metabolic, imaging, transit, endoscopy, breath, stool, or laboratory evaluation was completed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 7 of 15 | GI / fuel / bowel - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|---|--|
| ☐ GI specialist note | ☐ Imaging/endoscopy |
| ☐ Motility/transit study | ☐ Nutrition/metabolic laboratory record |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|--------------------------------------|--|---|
| ☐ food/intake | ☐ illness | ☐ sleep loss |
| ☐ medication | ☐ travel/schedule | ☐ puberty/hormones |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 8 of 15 | ENT / hearing / airway

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01	Ear infections, fluid, tubes, hearing change, tinnitus, or audiology follow-up has occurred					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
02	Sinus, mastoid, adenoid, tonsil, congestion, secretion, mouth breathing, or airway burden occurs					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
03	Snoring, apnea concern, drooling, hoarse/nasal voice, or another voice or breathing change is present					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
04	ENT, hearing, or airway state appears to affect sleep, balance, feeding, communication, or school access					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			
05	ENT surgery, cultures, pathology, tympanometry, imaging, sleep/airway study, or specialist evaluation was completed					
RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 8 of 15 | ENT / hearing / airway - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ Audiology/tympanometry

☐ ENT evaluation

☐ Sleep/airway study

☐ Imaging or operative record

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ infection

☐ allergy

☐ sleep

☐ season/weather

☐ procedure

☐ fatigue

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 9 of 15 | Motor / tone / gait / vision

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Low, mixed, or increased tone; stiffness; tremor; tics; weakness; or complex movements are observed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Sitting, crawling, walking, coordination, motor planning, balance, gait, laterality, or endurance developed differently

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Glasses, refractive difference, amblyopia, strabismus, oculomotor, visual-motor, or depth-perception concern was identified

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Dizziness, motion sensitivity, vestibular concern, falls, pain, fracture, contracture, or loss of movement access occurred

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Motor or visual access changes with illness, seizure/spell, sleep loss, pain, medication, heat, or exertion

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 9 of 15 | Motor / tone / gait / vision - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|--|---|
| ☐ Neurology/PT/OT | ☐ Orthopedic/rehabilitation record |
| ☐ Ophthalmology/neuro-ophthalmology | ☐ Vestibular or gait evaluation |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|--|--|--|
| ☐ illness | ☐ sleep/fatigue | ☐ pain |
| ☐ seizure/event | ☐ visual/motion demands | ☐ heat/exertion |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 10 of 15 | Behavior / sensory

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Anxiety, rigidity, meltdown, aggression, self-injury, shutdown, freeze, or reduced responsiveness occurs

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Noise, texture, movement, pressure, visual demands, clothing, food, or temperature affects regulation

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Pain, interoception, communication access, task demand, environment, or mental-health context may alter the observable behavior

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Function differs between baseline, increasing demands or active conditions, an event, and recovery

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Specific supports reliably improve safety, communication, comfort, regulation, or return toward baseline

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 10 of 15 | Behavior / sensory - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|--|---|
| ☐ Behavioral/mental-health note | ☐ OT sensory profile |
| ☐ School support plan | ☐ Context/state log |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|--|--|--|
| ☐ sensory demands | ☐ transition/change | ☐ school demand |
| ☐ pain/GI | ☐ illness | ☐ sleep/fatigue |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 11 of 15 | Immune / skin / mucosal

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Infections are recurrent, prolonged, unusually severe, or followed by a long recovery

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Antibody response, vaccine response, allergy, asthma, inflammatory, or other immune testing was completed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Eczema, rash, itching, bruising, skin picking, slow healing, or infection after skin injury occurs

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Oral, airway, GI, genital, or other mucosal symptoms, ulcers, fragility, or barrier concerns occur

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Immune, skin, or mucosal findings change with infection, medication, season/allergen, sleep loss, or recovery

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 11 of 15 | Immune / skin / mucosal - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ Immunology/allergy note

☐ Laboratory/culture record

☐ Dermatology record

☐ Infection and recovery timeline

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ infection

☐ season/allergen

☐ medication

☐ sleep loss

☐ skin/mucosal injury

☐ recovery period

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 12 of 15 | Autonomic / cardiac / urinary / temperature

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Heat/cold sensitivity, sweating, flushing, pallor, mottling, dizziness, or cold hands/feet occurs

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Heart rhythm, murmur, palpitation, fainting, slow/fast heart rate, or exercise tolerance raised concern

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Urine holding, urgency, accidents, retention, reduced output, dehydration, recurrent UTI, or renal concern occurs

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Event-level position, breathing, color, heart rate, blood pressure, oxygenation, temperature, awareness, and recovery were described

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Autonomic, cardiac, urinary, or temperature features change with illness, sleep, hydration, medication/anesthesia, heat, or hormones

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 12 of 15 | Autonomic / cardiac / urinary / temperature - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ ECG/echo/Holter

☐ Cardiology evaluation

☐ Urology/renal evaluation

☐ Orthostatic/autonomic testing

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ heat/cold

☐ illness

☐ hydration

☐ GI state

☐ procedure/medication

☐ exertion

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 13 of 15 | Growth / endocrine / puberty / bone

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Height, weight, BMI, head growth, growth velocity, or another growth trajectory prompted evaluation

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 Thyroid, growth-axis, adrenal, glucose, vitamin, mineral, or other endocrine testing was completed

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Early, delayed, or difficult puberty; menstrual management; or hormone-linked change is relevant

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Fracture, growth-plate injury, low bone density, bone age, DEXA, vitamin D/calcium, or skeletal evaluation occurred

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Nutrition, mobility, medication, puberty, endocrine state, or bone health appears to affect function or recovery

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 13 of 15 | Growth / endocrine / puberty / bone - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|--|---|
| ☐ Growth chart | ☐ Endocrinology note/labs |
| ☐ Bone age/DEXA | ☐ Fracture or bone-health record |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|---------------------------------------|---|--|
| ☐ growth phase | ☐ puberty/hormones | ☐ nutrition |
| ☐ medication | ☐ illness | ☐ mobility/weight-bearing |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 14 of 15 | Medication / anesthesia

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 A medication, dose/formulation change, supplement, sedation, anesthesia, or procedure was followed by a meaningful change

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 The reason for the exposure, dose, route, timing, co-medications, and concurrent physiological loads are documented

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 Paradoxical alerting, prolonged effect, sedation resistance, adverse event, benefit, no change, or mixed response occurred

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Objective measures and the specific target function were defined before direction was judged

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 Duration, recovery, recurrence, counterexamples, stop rules, and clinician follow-up are documented

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 14 of 15 | Medication / anesthesia - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

- | | |
|---|--|
| ☐ Medication administration record | ☐ Anesthesia/procedure record |
| ☐ Dose timeline | ☐ Clinician follow-up |

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

- | | | |
|---|--|---|
| ☐ baseline state | ☐ illness | ☐ sleep |
| ☐ GI/nutrition | ☐ co-medication | ☐ procedure/recovery |

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



Clinical area 15 of 15 | Function / school / adult

Fifteen clinical areas organize these prompts; they do not imply that any item is expected in ASH1L.

HOW TO READ A BLANK

A blank means not answered. It never means absent. Choose a response and a source separately. Use age/date and context when they matter.

01 Communication, learning, self-care, mobility, safety, or participation supports are needed or vary by setting

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

02 IEP, school testing, therapy goals, AAC, accommodations, supervision, or equipment supports are documented

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

03 A skill is present but access changes with state, environment, task demand, pain, fatigue, or communication support

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

04 Adult education, work, living support, health-care transition, community participation, or caregiver continuity is relevant

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			

05 The person's priorities, quality of life, strengths, reliable supports, and meaningful outcomes are recorded

RESPONSE	☐ Yes	☐ No	☐ Not sure	☐ Not assessed	☐ N/A	☐ Prefer not
SOURCE	☐ Person/family	☐ Original record	☐ Clinician	☐ School/therapy	☐ Multiple	☐ Other/unclear
AGE / DATE			CONTEXT / NOTE			



Clinical area 15 of 15 | Function / school / adult - source, context & impact

Add only what is useful. Formal testing and family observation are both valuable, but they are recorded as different source types.

ASSESSMENTS OR RECORD TYPES

Check completed, available, or relevant items.

☐ IEP/school record

☐ Adaptive testing

☐ Therapy/AAC record

☐ Adult transition or function record

FORMAL RESULT OR RECORD WORDING

Copy wording if helpful; do not interpret a report here.

CONTEXTS THAT MAY CHANGE ACCESS OR SEVERITY

☐ home

☐ school/work

☐ community

☐ fatigue/pain

☐ communication support

☐ transition/change

BASELINE OR USUAL PATTERN

what is typical

CURRENT IMPACT ON COMFORT, ACCESS OR PARTICIPATION

WHAT HELPS / WHAT MAKES IT HARDER

WHAT A CLINICIAN, SCHOOL OR RESEARCHER SHOULD NOT MISS



SECTION 05

Responses & change over time

Document chronology around medication, anesthesia, procedures, illness, other active conditions or demands, and recovery. This section supports pattern recognition, not causal conclusions.

MODULES IN THIS SECTION

Medication and procedure response

8-12 min

Event timeline

10-15 min

Baseline to recovery

8-12 min



Medication & procedure response

Record what happened, when, and the source. Do not use this page as a treatment plan.

CHRONOLOGY IS NOT CAUSATION

A response after a medication, procedure, infection, immunization, or other event is recorded as a time-linked observation unless a clinician or documented analysis establishes more.

MEDICATION / PROCEDURE / ANESTHESIA AND DATE

REASON IT WAS USED

BASELINE BEFORE THE EVENT

WHAT CHANGED AND HOW SOON

SYSTEMS AFFECTED AND OBJECTIVE MEASURES, IF ANY

RECOVERY, STOP-RULES OR CLINICIAN FOLLOW-UP

SOURCE: OBSERVATION, ORIGINAL RECORD OR CLINICIAN REPORT



Treatment and response history

Use one row per treatment or intervention. Continue details on the following timeline pages.

PATTERN OR LIMITATION THAT SHOULD BE INTERPRETED CAUTIOUSLY



Baseline -> active factors -> event -> measurement -> recovery

Describe one important window. Separate what was observed from what was measured.

01

BASELINE

What was usual before the window?

02

CONTEXT / ACTIVE FACTORS

Sleep, GI, illness, pain, school, sensory, medication, heat, hormones, or other context

03

EVENT / CHANGE

What changed, and when?

04

MEASUREMENT

What was measured, by whom, and with what result?

05

RECOVERY

Return to baseline, new baseline, partial recovery or still changing

SOURCE AND CONFIDENCE / LIMITATIONS



Repeated event timeline

Use a row for each event. Similar-looking events may have different contexts or sources.

PATTERN THAT DOES NOT FIT A ROW

--



SECTION 06

Communication, feeding & lifespan

Document communication access, speech and language, oral-motor and feeding skills, AAC, and the age modules that fit. Complete only relevant ages.

MODULES IN THIS SECTION

Communication, feeding & AAC

20-35 min

Age module(s)

8-15 min each

Earlier ages

optional recall



Communication profile

Describe how the person communicates across familiar and unfamiliar settings.

COMMUNICATION STRENGTHS AND PREFERRED MODES

HOW YES, NO, STOP, PAIN, HELP AND CHOICE ARE EXPRESSED

SPEECH CLARITY, CONSISTENCY, MOTOR SPEECH OR FLUENCY

RECEPTIVE LANGUAGE / WHAT IS UNDERSTOOD

EXPRESSIVE LANGUAGE / HOW IDEAS ARE SHARED

HOW COMMUNICATION CHANGES WITH STATE, SETTING OR PARTNER



Language, cognition, literacy & social communication

Record current access and variability without assuming that speech output equals understanding.

PROCESSING TIME, ATTENTION AND WORKING MEMORY

WORD FINDING, SENTENCE FORMULATION AND NARRATIVE

FOLLOWING DIRECTIONS, QUESTIONS AND ABSTRACT LANGUAGE

READING, DECODING, COMPREHENSION AND WRITING

CONVERSATION, RELATIONSHIPS AND SOCIAL INTERPRETATION

FORMAL EVALUATIONS, DATES, SCORES AND SOURCE LIMITS



Oral-motor, feeding & swallowing

Document skill, safety, endurance, texture and source. This page does not replace a swallowing evaluation.

SAFETY

New or urgent choking, breathing, dehydration, or nutrition concerns require direct clinical care.

EARLY BREAST / BOTTLE / TUBE / MIXED FEEDING HISTORY

CURRENT FOOD AND LIQUID TEXTURES, VOLUME AND ENDURANCE

BITING, CHEWING, TONGUE MOVEMENT, POCKETING OR POSTURE

COUGHING, CHOKING, GAGGING, DROOLING OR SWALLOW TIMING

SELF-FEEDING, UTENSILS, SENSORY RESPONSE AND MEALTIME ACCESS

FEEDING / SWALLOW EVALUATIONS, THERAPY AND SOURCE



AAC & communication access

Complete at any age when speech is limited, inconsistent, effortful, or supported by another system.

CURRENT AAC: GESTURES, SIGN, PICTURES, LOW-TECH OR SPEECH-GENERATING DEVICE

VOCABULARY, ACCESS METHOD, MOTOR / VISION / HEARING NEEDS

INDEPENDENT, PROMPTED OR PARTNER-SUPPORTED USE

HOME, SCHOOL, CLINIC AND COMMUNITY AVAILABILITY

HOW PARTNERS MODEL, WAIT, REPAIR AND HONOR COMMUNICATION

BACKUP SYSTEM, CHARGING, MOUNTING AND LOSS-OF-ACCESS PLAN

HOW AAC ACCESS CHANGES WITH ILLNESS, FATIGUE OR MOVEMENT



Birth-5 years

Complete this page for the current age or as optional developmental recall. Note whether information is current, recalled, or record-based.

AGE MODULE, NOT A CHECKLIST

Prompts organize family observations and formal assessments. They do not define expected ASH1L features or developmental outcomes.

SOCIAL ATTENTION, JOINT ATTENTION AND PLAY

VOCAL PLAY, BABBLING, WORDS OR SYMBOLS

IMITATION, PRETEND PLAY AND FLEXIBLE PLAY

FEEDING, ORAL-MOTOR AND SELF-FEEDING

SENSORY REGULATION, SLEEP AND TRANSITIONS

EARLY-INTERVENTION GOALS AND RESPONSE



Ages 6-10

Complete this page for the current age or as optional developmental recall. Note whether information is current, recalled, or record-based.

AGE MODULE, NOT A CHECKLIST

Prompts organize family observations and formal assessments. They do not define expected ASH1L features or developmental outcomes.

DECODING, READING FLUENCY AND COMPREHENSION

EXPRESSIVE / RECEPTIVE LANGUAGE AND WORD FINDING

NARRATIVE, WRITING AND ORGANIZATION

FRIENDSHIPS, PLAY AND SOCIAL COMMUNICATION

SCHOOL ACCESS, FATIGUE AND STATE-RELATED VARIABILITY

THERAPY / EDUCATION GOALS AND WHAT HELPS



Ages 10-15

Complete this page for the current age or as optional developmental recall. Note whether information is current, recalled, or record-based.

AGE MODULE, NOT A CHECKLIST

Prompts organize family observations and formal assessments. They do not define expected ASH1L features or developmental outcomes.

READING FOR MEANING AND NONLITERAL LANGUAGE

ABSTRACT LANGUAGE, REASONING AND PROBLEM SOLVING

CONVERSATION, RELATIONSHIPS AND SELF-ADVOCACY

EXECUTIVE FUNCTION, WRITING AND MULTI-STEP DEMANDS

PUBERTY, SLEEP, FATIGUE AND CHANGING ACCESS

SCHOOL / THERAPY GOALS AND TRANSITION PLANNING



Ages 15-adult

Complete this page for the current age or as optional developmental recall. Note whether information is current, recalled, or record-based.

AGE MODULE, NOT A CHECKLIST

Prompts organize family observations and formal assessments. They do not define expected ASH1L features or developmental outcomes.

CURRENT COMMUNICATION AND DECISION SUPPORT

READING, WRITING, MONEY, SCHEDULES AND TECHNOLOGY

EDUCATION, TRAINING, WORK OR DAY PARTICIPATION

RELATIONSHIPS, COMMUNITY, INTERESTS AND BELONGING

FEEDING, HEALTH SELF-MANAGEMENT AND APPOINTMENTS

GOALS FOR INDEPENDENCE, SUPPORT AND QUALITY OF LIFE



SECTION 07

Adult, function & safety

Support transition, daily function, decision-making, safety, and the practical information clinicians and schools may otherwise miss.

MODULES IN THIS SECTION

Transition & decision support

8-12 min

Daily function

8-12 min

Safety & overlooked information

10-15 min



Adult transition & supported decision-making

Use at any age when planning adult services, healthcare transition, decision support or caregiver continuity.

PRESUME PARTICIPATION

Record how to include the person directly and what support makes decision-making accessible. A diagnosis alone does not determine decision capacity.

PERSON'S OWN GOALS, PREFERENCES AND COMMUNICATION ACCESS

HEALTHCARE TRANSITION: CURRENT AND FUTURE PROVIDERS

DECISIONS MADE INDEPENDENTLY, WITH SUPPORT OR BY AN AUTHORIZED PERSON

LEGAL OR PRACTICAL ARRANGEMENTS, IF THE PERSON CHOOSES TO SHARE

BENEFITS, SERVICES, TRANSPORTATION, HOUSING OR CAREGIVER CONTINUITY

EMERGENCY PLAN AND WHO CAN COMMUNICATE THE PERSON'S BASELINE



Daily function & participation

Describe what the person does, what support is used, and how access changes across settings or states.

PERSONAL CARE: EATING, DRESSING, TOILETING, HYGIENE

MOBILITY, TRANSFERS, COMMUNITY NAVIGATION AND TRANSPORT

COMMUNICATION, PHONE / COMPUTER AND EMERGENCY ACCESS

MONEY, MEDICATIONS, APPOINTMENTS AND SCHEDULES

HOME, EDUCATION, WORK, VOLUNTEERING OR DAY PARTICIPATION

WHAT CHANGES FUNCTION: FATIGUE, ILLNESS, PAIN, SENSORY OR TASK DEMANDS



Safety, comfort & urgent communication

Use this page to communicate baseline, pain signals, and what helps during urgent care.

URGENT CARE

Follow the person's emergency plan and seek urgent evaluation for breathing difficulty, loss of consciousness, repeated seizures, serious injury, severe dehydration, or any change that feels unsafe.

HOW THE PERSON SHOWS PAIN, FEAR, DISTRESS, YES, NO AND STOP

WANDERING, FALL, CHOKING, SEIZURE, ALLERGY OR OTHER KNOWN SAFETY PLAN

MEDICATION, ANESTHESIA OR PROCEDURE INFORMATION TO VERIFY BEFORE USE

SENSORY, POSITIONING OR COMMUNICATION SUPPORTS IN URGENT CARE

WHO KNOWS BASELINE AND MAY BE CONTACTED

WHAT WOULD REQUIRE DIRECT CLINICAL OR EMERGENCY ACTION



What clinicians, schools & programs may miss

Describe baseline and access in practical terms. Focus on what changes interpretation, safety and participation.

FOR CLINICIANS: BASELINE, PAIN / ILLNESS SIGNALS AND ATYPICAL PRESENTATION

FOR CLINICIANS: TEST LIMITS, ACCESS SUPPORTS AND UNRESOLVED QUESTIONS

FOR CLINICIANS: RECORDS OR PEOPLE THAT CAN VERIFY THIS INFORMATION

FOR SCHOOLS / PROGRAMS: STRENGTHS AND CONDITIONS FOR ENGAGEMENT

FOR SCHOOLS / PROGRAMS: COMMUNICATION, PROCESSING, MOTOR OR STATE VARIABILITY

FOR SCHOOLS / PROGRAMS: EFFECTIVE SUPPORTS, SAFETY AND PERSON-DEFINED GOALS



SECTION 08

Review & share

List where records are held, prepare a concise final summary, update uncertainty, and choose what is useful for the next reader.

MODULES IN THIS SECTION

Records & final summary

10-15 min

Final handoff check

8-12 min

Close & save

3-5 min



Detailed records inventory

List records, dates, and locations so you can find them later. Share a record only when it is needed and through a secure method.

NOTES ABOUT PRIVACY OR WHICH RECORDS TO SHARE

--



Final one-page priority summary

Update this after completing relevant modules. Share this page alone when a concise handoff is enough.

NAME OR CASE LABEL / AGE / DATE UPDATED

STRENGTHS, INTERESTS AND PERSON-DEFINED GOALS

TOP THREE CURRENT PRIORITIES

USUAL BASELINE AND IMPORTANT STATE-RELATED CHANGE

CURRENT SAFETY / COMMUNICATION / ACCESS SUPPORTS

MOST USEFUL NEXT MEASUREMENT, RECORD OR CONVERSATION

SOURCE LIMITS: WHAT IS OBSERVATION VS ORIGINAL RECORD



Final review before sharing

Update anything unclear, outdated, or incomplete. Remove details that the intended reader does not need.

INFORMATION TO UPDATE, CLARIFY OR COMPLETE

INFORMATION THAT SHOULD NOT LEAVE THE FAMILY'S PRIVATE COPY

CHECK EACH PART OF THIS HANDOFF

The purpose is clear	☐ Yes	☐ No	☐ Not sure	☐ Discuss
The person is described respectfully	☐ Yes	☐ No	☐ Not sure	☐ Discuss
Unneeded identifiers are removed	☐ Yes	☐ No	☐ Not sure	☐ Discuss
Dates and source descriptions are accurate	☐ Yes	☐ No	☐ Not sure	☐ Discuss
Uncertainty is marked	☐ Yes	☐ No	☐ Not sure	☐ Discuss
Only useful pages are included	☐ Yes	☐ No	☐ Not sure	☐ Discuss
A private copy is saved	☐ Yes	☐ No	☐ Not sure	☐ Discuss

NOTES FOR THIS HANDOFF

READY FOR A USEFUL HANDOFF

Send the smallest set of pages that answers the question in front of the intended reader.



Final review before you close the file

Save your copy, check the details that matter, and record the next step.

- ☐ I saved a copy and confirmed that entered text remains after reopening.
- ☐ I completed only the sections that are useful.
- ☐ I removed names and details the intended reader does not need.
- ☐ I kept family observations separate from original records and professional reports.
- ☐ I marked information that is uncertain or out of date.
- ☐ The document states who it is for and why.
- ☐ I included the relevant safety plan or contact information.
- ☐ I recorded what needs follow-up.

NAME / ROLE, OPTIONAL

DATE REVIEWED

FINAL NOTES OR NEXT STEPS

READY TO USE

Thank you for documenting the person carefully. Update this copy whenever the baseline, priorities, or plan changes.