

Guidelines for Developing an AACPDM Care Pathway

Definition of an AACPDM care pathway: A practical summary, including an algorithm, of evidence informed guidelines or the best evidence for an aspect of care/services for individuals with childhood-onset disabilities to inform clinical practice.

The care pathway will consist of four sections:

- i) a) A “bottom line” evidence informed summary (two page maximum length) that provides key information to understand the flow of the algorithm and includes the following sections (if relevant to the health condition or service):
 - A statement of the health condition or service/care need and why it is important including typical clinical outcomes/natural history and impact on the individual
 - An outline of the intended Target users AND Target Clinical Providers of the care pathway
 - Section on Assessment/Diagnosis (multi or interdisciplinary perspectives)
 - Evidence-informed Treatment Options (including a range of treatment options; based on evidence informed guidelines or if not available based on consensus of the clinical expert panel).
- b) Algorithm: This component will outline a logical sequence/path from assessment to treatment that will partner with the information in the bottom line summary.
- ii) Published Evidence: Links to peer-reviewed published therapeutic evidence (systematic reviews and clinical practice guidelines) informing the ‘Care Pathway’ and a summary of recent evidence published after the systematic reviews (prepared by the pathways team).
- iii) Practical Tools and Plain Language Summary: This section provides practical tools/documents for clinicians to use the pathway including a lay description of the bottom line summary for individuals with childhood-onset disabilities and caregivers.
- iv) Acknowledgements: This section lists all contributors and institutions that assembled the care pathway, including any potential conflicts of interest.

When to create a care pathway?

A care pathway can be developed in (but not limited to) the following circumstances:

- The pathway focuses on an important health condition that individuals with childhood-onset disabilities experience or a service that they seek;
- When multiple treatment options for a condition exist;
- A clinical practice guideline or systematic review has been recently published (within the last 3 years) for a condition; if no systematic review(s) exist for a condition the care pathway team will also need to complete a systematic review of the therapeutic evidence and post this review in section II. The pathway group is strongly encouraged to submit the systematic review as a peer-reviewed manuscript application when the evidence is of sufficient nature to warrant a publication. If a peer-reviewed manuscript is not planned this should be discussed and reviewed with the care pathway committee. If there is agreement not to submit a peer-reviewed manuscript, a systematic review document will need to be filed as a pdf in Section II.

How to create a care pathway?

STEP 1: A volunteer team of greater than 10 experts from multiple disciplines relevant to the care pathway will form and lead the development of a care pathway focused on a health condition/service/care need that is of relevance to individuals with childhood-onset disabilities. A team lead will be identified. The volunteer team should have expertise in the clinical management of the condition and research/methodology knowledge. The team will declare any potential conflicts of interest and these will be reviewed by the team lead. The team

should include at least one stakeholder (individual with a childhood-onset disability or family member). The team can also be layered in two parts and include a core team that is primarily responsible for developing the 'Care Pathway' and a consultation team that will review final drafts of the Care Pathway sections. The group providing the stakeholder consultation outlined in step 7 below can also be part of a consultation team providing early and ongoing input throughout the Care Pathway development. To develop a care pathway at least one systematic review on the therapeutic interventions included in the care pathway should be published on the topic. If a systematic review is not yet available, the team will also need to commit to completing a systematic review for section II.

STEP 2: An [application](#) will be made by the team to the AACPDM care pathways committee through the AACPDM office to request permission to develop a care pathway for the AACPDM website. The application will include a statement of objective(s) and a clear description of the health condition/service/care need that will be the area of focus, the intended target population and expected benefit(s) or outcome(s) as well as the target clinical providers of the care pathway. The team will also define the population (e.g. age range, diagnosis) addressed by the care pathway and a brief outline of the planned methods for the development of the Care Pathway. Please note that the AACPDM board has created an AACPDM Care Pathway Development Grant that will be awarded on an annual basis (application in the fall with award decisions made for the following spring) over the next 3 years. The team can indicate on the [application form](#) if they wish to be considered for this grant. These applications will be adjudicated by the AACPDM Care Pathway committee and the criteria for review are included in the application form.

STEP 3: A literature review will be completed by the expert team or an identified research librarian to identify all published systematic reviews, meta-analyses, published clinical practice guidelines, and relevant single studies (if a systematic review is available the librarian will only identify new studies published following the systematic review timeframe). A summary of search methods and copies of the relevant literature will be sent electronically to the team. Online tools to help organize the literature for systematic reviews can be found at: www.evidencepartners.com/products/distillersr-systematic-review-software
<https://www.covidence.org/>

STEP 4: The expert team will review the literature provided (see Step 5 ii below).

STEP 5: The expert team will develop a draft of the Bottom Line Summary (outlined above).

- i) The title of the 'Care Pathway' will include the list of core contributors. The Care Pathway lead will be listed first followed by a designation of lead in brackets.
- ii) For the section on assessment and diagnosis, if relevant, the team will comment briefly on the psychometric properties of the measurement tools from a screening and diagnostic perspective. If a systematic review of the assessment/diagnostic tools is available this can be referenced. They will make a recommendation on best practice for assessment/diagnosis for this particular health care service/need/condition informed by knowledge of the measurement properties interacting with clinical expertise. Assessment instruments in the NINDS/AACPDM Common Data Elements for Cerebral Palsy may be referenced, if relevant.
- iii) For the section on treatment options the team will review the systematic reviews/meta-analyses/published guidelines and new published evidence and determine the level of evidence for each treatment. Levels of evidence will range from established/effective (color coded **green**), possibly or probably effective (color coded **yellow**), data inadequate but still recommended by the clinical expert team panel (color coded **purple**), and not effective (color coded **red**). The method of determining the level of evidence will be dependent on the methodology utilized for the systematic review. If a published systematic review/published guideline is not available for a specific component of the pathway, the team will utilize a methodology of their choice (e.g.

<http://training.cochrane.org/path/grade-approach-evaluating-quality-evidence-pathway>, [AACPDM Systematic Review methodology](#), [AAN Clinical practice guideline](#), [AGREE II](#)) to review and color code that aspect. They will state which system they used. The team will embrace an evidence informed process whereby they will prioritize areas that are supported by evidence but also integrate clinical expert opinion for areas of treatment where evidence is lacking. They will state the methodology they utilized in their bottom line summary. If a particular element of the pathway is guided by a specific reference these should be numbered in the pathway and referenced at the end of the pathway. Systematic reviews that guide the entire pathway should be identified and referenced with the pathway as well as links provided to the systematic review for Section II.

- iv) A written summary of the 'new' literature published after previous systematic reviews, which is systematically searched and identified, will also need to be completed by the pathway team and posted in Section II. This can be done as a manuscript for submission to a journal or as a word document.

NOTE: Include references for all steps in the care pathway

STEP 6: An algorithm will be constructed in a flow chart format utilizing any preferred software (e.g. MS PowerPoint®, MS Visio®, [LucidChart](#),) and saved as a pdf or jpg file for uploading. The structure or format of the algorithm will be dependent on the condition and the suggestions from the expert team. The treatment option boxes should be "filled" in with the appropriate evidence color as outlined above. The box should include the core components required by the health professional for making treatment decisions (e.g. GMFCS level, contraindications). A maximum page length for the algorithm is two pages (embedded links will be allowed). Please note that once an algorithm is finalized it can be formatted by the AACPDM pathway team support person (office staff).

STEP 7: The bottom line summary, care pathway and the systematic literature review will be circulated to a stakeholder group for review. The stakeholder group will be identified by the pathway team and should be representative of individuals with childhood-onset disabilities, families/caregivers, and community stakeholders. A teleconference call will be organized by the AACPDM pathway person with the expert team and the stakeholder group to review the pathway (bottom line summary and pathway) to provide input and suggestions and where appropriate the pathway will be revised.

STEP 8: Develop the content for the Care Pathway webpages. The expert team will develop the following items that will be posted online in the appropriate sections:

- I. Bottom-line summary, Algorithm
- II. Links to published systematic reviews/clinical practice guidelines, and a care pathway team generated written summary of recent research
- III. Links to practical tools (i.e. fact sheets, videos, podcasts, websites) and a one paragraph plain language summary
- IV. List all individual experts that assisted in developing the care pathway, listing their degree and institutional affiliation(s). Any potential conflicts of interest will also be outlined in this section. At the top of Section IV the preferred citation format will also be listed (please see example in current 'Care Pathways' posted online. If a Care Pathway team is layered with a core team and consultation team this will be reflected in the acknowledgment section. The primary Care Pathway team will be the authors listed in section 1.

STEP 9: The lead for the team will complete the Care Pathway checklist, including the Care Pathway application and submit all files within a two-year timeframe to the AACPDM office in order to be distributed and reviewed by the care pathway committee. The committee will review the submitted documents and

provide feedback. The committee may request the 'Care Pathway' development team initiate a broader consensus building process for the Care Pathway (e.g. survey of a broader identified international clinical expert group; survey of the AACPDm membership). Revisions will be made to the pathway if required.

STEP 10: The committee will forward the pathway to the board for acceptance. A disclaimer will be added to the pathway and then the AACPDm pathway support person will post the pathway on the website. The expert team will verify the functionality of the online care pathway and approve the website live date included on the pathway. Copyright of the 'Care Pathway' will be assigned to the AACPDm.

STEP 11: A blast email will be circulated to the AACPDm membership and networks that a new pathway has been posted. The AACPDm will allow for feedback on the care pathway at which point any comments/feedback with regards to the pathway will be distributed to the pathway team for a direct response. The AACPDm office will forward the emails received to the pathway team leader on a monthly basis for the first three months and then every 6 months. The pathway team lead or delegate is encouraged to respond to the inquiry and also consider any potential revision to the pathway process based on feedback. The Care Pathway can be edited prior to the 3-year review of the pathway.

STEP 12: The AACPDm staff will request the expert team regroup at 2 years following the online posting of the pathway to repeat steps 1 through 11 to update the pathway. The evaluation results of the care pathway's online performance will be provided to the team for consideration of potential pathway modifications. New members to the expert team will be recruited if required. If a pathway is not reviewed by the three year mark it will be removed by the AACPDm staff until a review has been completed.