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 “bottom line” summary (two page maximum length) that outlines key important information to understand the flow of the algorithm providing information in the following areas (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
   - Evidence-informed Treatment Options (including a range of treatment options)

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 caregivers.

iv) Acknowledgements: This section lists all contributors and institutions that assembled the care pathway.

**When to create a care pathway?**

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

- The pathway focuses on an important health condition or service that individuals with childhood-onset disabilities have or seek service for;
- Multiple treatment options for a condition exist;
- A clinical practice guideline or systematic review has been published 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 pathway steering group. 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 between 5 to 10 experts from multiple disciplines 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. To develop a care pathway at least one systematic review 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 as well as the intended target population and target clinical providers of the care pathway. The team will also define the population (e.g. Age range, diagnosis) of the care pathway.

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 randomized controlled trials (if a systematic review is available the librarian will only identify new RCTs published following the systematic review timeframe). Copies of the relevant literature will be sent electronically to the team. An online tool to help organize the literature for systematic reviews can be found at: https://www.covidence.org/.

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

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

i) 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. 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.

ii) 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. GRADE system, 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.

iii) 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. recommended dosage and potential side effects). A maximum page length for the algorithm is two pages. 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. 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 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.

**STEP 9:** The lead for the team will complete the Care Pathway checklist, including the Care Pathway application and submit all files to the AACPDM office in order to be distributed and reviewed by the care pathway steering group (eventually this will transition to the AACPDM care pathway committee) for review and feedback and revisions made to the pathway if appropriate.

**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.

**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.